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Special issue: Quality of life in a social context

Edited by: Roy I Brown, Rhonda M Faragher, and Joav Merrick

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EDITORIAL

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Quality of life in a social context

Roy I Brown, BSc(Gen), BSc(Spec), DipPsych, PhD*[1,2,3,4], Rhonda M Faragher, BSc, BEdSt(Hons1), PhD[5], and Joav Merrick, MD, MMedSci, DMSc[6,7,8,9]

[1]University of Calgary, Canada
[2]Flinders University, Australia
[3]School of Child and Youth Care, University of Victoria, Canada
[4]University of New England, Australia
[5]Faculty of Education, Australian Catholic University, Canberra, Australia
[6]National Institute of Child Health and Human Development, Jerusalem
[7]Office of the Medical Director, Health Services, Division for Intellectual and Developmental Disabilities, Ministry of Social Affairs and Social Services, Jerusalem
[8]Division of Pediatrics, Hadassah Hebrew University Medical Center, Mt Scopus Campus, Jerusalem, Israel
[9]Kentucky Children's Hospital, University of Kentucky College of Medicine, Lexington, Kentucky, United States of America

Introduction

This special issue represents the second in the series on intellectual and developmental disability and quality of life and the possibilities of application in a wide range of areas of disability and also across a variety of issues relating to human services. The present series of articles deals with many practice issues, which are important for frontline intervention and support. These issues are also critical in terms of the need to match practice with policy to create integrated systems of delivery across the lifespan for individual and family needs where major challenges arise.

Issues of inclusion are discussed and in this context the danger is that without careful policy and practice development, community inclusion can falter and lead to exclusion. The need to bring different aspects of community service in all its forms is presented and discussed with practical examples. The breadth of application can better be understood, if we recognise the importance of the fine arts and recreation within this context. Also important are health issues, such as dealing with pain within a quality of life context, and aging. Aging is an increasingly important quality of life challenge, and one that is based on a lifespan context of individual development. To deal with individual needs when challenged in health and behaviour it is important to describe the methods of individual program planning as illustrated in this particular journal issue, again linking this to policy and its bonding with needs and supports at the "coalface".

Other papers are concerned with philosophical issues in the context of human rights and personal dignity. These are aspects which are often named in law and international declarations, but need ground support and practice to make effective, leaving many challenges in terms of delivery. The field of quality of life as currently seen is challenged to broaden its

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* ***Correspondence:*** Professor Roy I Brown, BSc(Gen), BSc(Spec), DipPsych, PhD, School of Child and Youth Care, University of Victoria, POBox 1700, STN CSC, Victoria, BC Canada V8W 2Y2. E-mail: royibrown@shaw.ca

approach using a wide range of research and practical means to bring about conceptual and practical changes locally, nationally and internationally. This is the challenge before us.

REVIEW ARTICLES

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Enhancing the quality of life of marginalized populations through employment

Rosemary M Lysaght, BSc(OT), MSc(Rehab), PhD (Education), OT Reg(Ont)*[1] and Virginie Cobigo, PhD, CPsych[2]

[1]Queen's University, School of Rehabilitation Therapy, Kingston

[2]University of Ottawa, School of Psychology and Centre for Research on Educational and Community Services, Ottawa, Canada

Abstract

Employment is a primary life role function of most adults, and is associated with a number of central elements of quality of life, such as productivity, income, emotional and physical well-being, and social connectivity. Many adults, however, are excluded from employment, are underemployed, or relegated to low income, low status positions that fail to contribute to an adequate quality of life. Success in this and other vital social roles can be understood as a function of the dynamic interaction between a number of individual and environmental factors that underpin social participation. This paper presents a theoretical model of social inclusion that was developed in the context of intellectual and developmental disability. The model has at its core social role participation, and helps to both explain and offer insights as to how optimal inclusion and social role success can contribute to quality of life across a broad range of populations.

Keywords: Quality of life, intellectual disability, employment

Introduction

Employment is a central feature of life for most working age adults, and can contribute to full and rewarding social participation. Even for people with intellectual and developmental disabilities (IDD), who have historically struggled to obtain meaningful employment, being employed is preferred to unemployment (1-3). Employment has been demonstrated to be directly related to a number of key elements of quality of life including enhanced productivity, sustainable income, improved physical and mental health, and social connectivity. Many adults, particularly those with intellectual disabilities, fail to achieve satisfying employment, instead enduring undesired periods of unemployment or finding themselves underemployed in low income,

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* ***Correspondence:*** Rosemary M Lysaght, PhD, OT Reg (Ont), School of Rehabilitation Therapy, Queen's University, Kingston, ON Canada K7L 3N6. E-mail: lysaght@queensu.ca

low status positions (4). Lack of employment income and low wages can lead to financial and social poverty, meaning that people lack not only the necessary income to satisfy basic needs, but that they lack the opportunity and funds to participate in many social activities (5). Although poverty and lack of socially valued roles is clearly identified within intellectual and developmental disabilities, it is equally experienced by those with absent, limited or precarious employment situations and contributes directly to the social marginalization experienced by many people with other disabilities, new immigrants, and those in excluded racial and cultural groups (5). This becomes an ongoing disadvantage that systematically reduces opportunity for future participation.

In this paper we will consider the features that lead to inclusion in employment, and how inclusion in productive roles in turn contributes to quality of life. Based on our model of inclusion, we will identify potential strategies for addressing employment marginalization and propose changes in policy and practice necessary to address quality of life through an employment approach.

Employment and quality of life

Quality of life (QOL) has been a focus of attention for the past half century. As a major construct of concern to sociologists, urban planners, policy makers, health researchers, and others, the factors that both constitute QOL, and the underlying conditions that contribute to achieving it, are of widespread interest. Researchers across these fields have made multiple attempts to define the construct, leading to a plethora of conceptual models and measurement tools.

A scoping review that looked at subjective measures of QOL (6) identified two central features of most operational definitions of QOL: happiness and satisfaction. A number of “antecedents” or sub-domains that lead to QOL were identified through this review, common factors among them being physical and mental health, socio-economic stability, fulfilling activities and ability to function, connections with other people, positive self-concept, and overall satisfaction (6). Efforts to measure QOL in objective terms have in fact been criticized (7,8), and a case made that subjective feelings of having a good quality of life are the only measure that really matter. Others note that there is little correlation between subjective and objective measures of QOL, and that therefore the two must be measured independently and/or each addressed within comprehensive measures (9, 10). Some researchers contend that most measures of quality of life focus on factors that contribute to subjective sense of quality of life, rather than the construct itself (11).

The World Health Organization (WHO) defines quality of life as “*individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*” (12, p. 1). This view is supported by an inter-disciplinary group of researchers who in 2008 proposed an integrative definition of QOL that also embraced subjective and objective aspects of the construct: “*Quality of Life (QOL) is the extent to which objective human needs are fulfilled in relation to personal or group perceptions of subjective well-being*” (9). Earlier definitions have also noted this in the context of intellectual and developmental disabilities (13,14) and other fields (15). This definition addressed the importance of satisfying basic human needs, and recognized that perceptions of QOL are inherently linked to social norms and expectations. Human needs are described as including subsistence, basic security, and affection.

These integrated definitions point out some important concepts. One, QOL perceptions are inherently linked to one’s environment, both objectively (socially determined standards of what represents QOL) and subjectively (internalized perceptions and expectations). Second, the concept is so complex that depending on the theoretical basis of the research, different combinations of tools may be necessary. Healthy People 2020, an initiative of the U.S. government, will use 3 distinct concepts to measure QOL: a global health measure, measures of subjective well-being, and measures of participation. Finally, it is clear that a whole range of intra- and inter-personal elements are fundamental to achieving a good QOL. All QOL measures appear to include intra- and inter-personal dimensions related to psychological well-being, social connection and/or belonging (12,16,17). For example, domains measured by the WHO index include physical and psychological health, independence, and social relationships. This broad attention to interpersonal functioning resonates with the view that inclusion is an integral part of QOL, even when it is not named or defined, or seen as an organizing concept in and of itself.

IDD researchers have studied QOL as a means of determining socially equitable outcomes for a population that historically was institutionalized, and was only in the past 50 years broadly expected to participate in society as full citizens (18). By understanding the components of QOL that are important to members of this population, it is possible to set about finding means of moving people towards satisfying those needs. Scales such as the Quality of Life Questionnaire (10) and the Comprehensive Quality of Life Scale (19) helped to establish benchmarks and targets for achieving acceptable QOL for people with intellectual disabilities, and monitoring the effectiveness of various interventions intended to improve social outcomes.

Employment is relevant to any discussion of quality of life, since several features of prominent models of quality of life include elements that may be interpreted as deriving from work such as personal development, material well-being (5,9,12,19)) and some include direct measures of work participation (10). From a material perspective, work is an important means of achieving income and self-sufficiency.

Some prominent economists have pointed out that the negative impacts of unemployment go beyond loss of income, impacting such quality of life factors as health, education, personal security and personal connectedness (20). Not only is employment culturally expected in most western societies, but it is a means of achieving a satisfying and high quality lifestyle. In contrast, adult financial dependency is socially stigmatized in most Western cultures.

Psychological theory refers to a variety of reasons why people work. The obvious motivation is economic, based on the intrinsic link between income and satisfaction of basic subsistence needs (21). A range of other extrinsic motivators have been identified, including materialism, cultural expectations, perceived social value of one’s work and that of the employing organization, among others (22,23).

Intrinsic motivators have also been identified and include love of the work itself, altruism, need to affiliate with others, and individual drive (23,24). Wilcock (25) cites research demonstrating the inherent need of people to be engaged and productive, and the negative outcomes observed when people lack purpose and occupational outlets. The many values of work were identified by Jahoda (24) in 1981:

> “First, employment imposes a time structure on the waking day; second, employment implies regularly shared experiences and contacts with persons outside the nuclear family; third, employment links individuals to goals and purposes that transcend their own; fourth, employment defines aspects of personal status and identity; and finally, employment enforces activity.” (p. 188)

A number of researchers have sought to understand the relationship between employment and quality of life. Studies conducted relative to employed and unemployed populations with a variety of health conditions, such as HIV AIDS, obesity and mental illness have consistently demonstrated higher quality of life ratings for those who are employed (26-28). In the area of IDD, researchers have looked at quality of life outcomes particularly with respect to people in sheltered vs. non-sheltered work situations, and for those who are working or not working.

Quality of life findings are consistently higher for those who are working versus not working, and for high functioning workers with IDD, quality of life is higher in community based settings (28-31). Assuming that work in the community provides greater challenge and variety, this final point seems consistent with the findings of a recent Canadian study of workers included in general population surveys, which demonstrated that health-related quality of life is compromised by underemployment. In that study, underemployment was interpreted as gaps between the capacity one has for work based on education, experience, credentials, and desired hours of work and the reality of one’s employment situation (32).

Understanding successful employment participation

Employment marginalization, or failure to successfully achieve desired and meaningful employment, is experienced by many people, particularly those in social groups that have traditionally been socially excluded. Marginalization is defined by noted sociologist Iris Marion Young as "the act of relegating or confining a group of people to a lower social standing or outer limit or edge of society", and involves people who differ from the dominant group in a society based on disability, aging, race and social class (33). She notes that marginalization results in exclusion from social contribution, and material deprivation, such that many or most marginalized people live in poverty. Thus, successful employment can be viewed as one element of successful social inclusion and participation.

The authors of this paper examined social inclusion and how it applies to different life contexts as part of a larger project examining social inclusion in persons with intellectual disabilities. An ecologically-based theoretical model (34) (see Figure 1) that was initially developed with respect to people with intellectual disabilities identifies individual and social factors contributing to social inclusion for any adult, and acquisition of meaningful social roles, such as employment. This is also seen as an important aspect of quality of life.

The model defines social inclusion as a dynamic interchange between environmental factors and personal characteristics that leads to role acquisition. Inclusion arises in the context of the social roles one holds, with social roles being defined as the functions and behaviours of an individual within a group. The roles one acquires emerge based on personal needs, preferences and expectations, and respond to the needs, expectations and preferences of agencies and individuals in the relevant community venues (e.g. employer, sports team, religious group). Individual interest and choice are fundamental to overall wellbeing, and are fundamental aspects of quality of life.

Participation and the inclusivity of that participation can also be mediated by a variety of formal and informal tools and structures such as legislation, education, and personal supports (35). The range of environments, possible roles and individual needs necessitate different forms of support. Tools and supports become particularly important in the case of persons in marginalized groups, where systemic efforts and rules to address such socially constructed barriers as stigma, lack of trust and fear are often needed.

Social inclusion can be achieved in all, some, or none of the roles we attempt. Successful role engagement results when the individual involved and people associated with the chosen roles perceive a successful and satisfying transaction at both interpersonal and instrumental levels. In such cases, the individual is capable and competent, draws satisfaction from the role performance, and their contributions and participation are valued and accepted by others in the environment. This mutual satisfaction leads to both trust and reciprocity between parties, and a sense of belonging on the part of the individual concerned. Clearly, individuals can be successfully satisfied and valued in some settings and roles and not others; they can be welcomed and needed in some roles, but find them dissatisfying; they can be competent and valued, but not feel belonging (36). Thus, social inclusion is a dynamic and relative process that relies on a delicate and ever-changing balance between the critical elements.

In the context of employment, we would interpret one's job as the social role in question. For the job match to be successful, the job or career would be selected based on having the right training and traits (*personal characteristics and skills*) as well as individual preference and needs, such as the remuneration level, opportunity to contribute, personal development opportunity and others (*personal expectations, choices and needs*).

Finding the right job depends on availability of jobs in the local market (*environment*) and the specific standards, preferences and workplace culture of the particular employer (*community expectations, choices and needs*). One must be the best candidate for the job, and be provided with fair and equitable opportunity based on both workplace rules and public regulations (*tools*). Individual supports, like a life coach or referral sources may help the individual connect with the job.

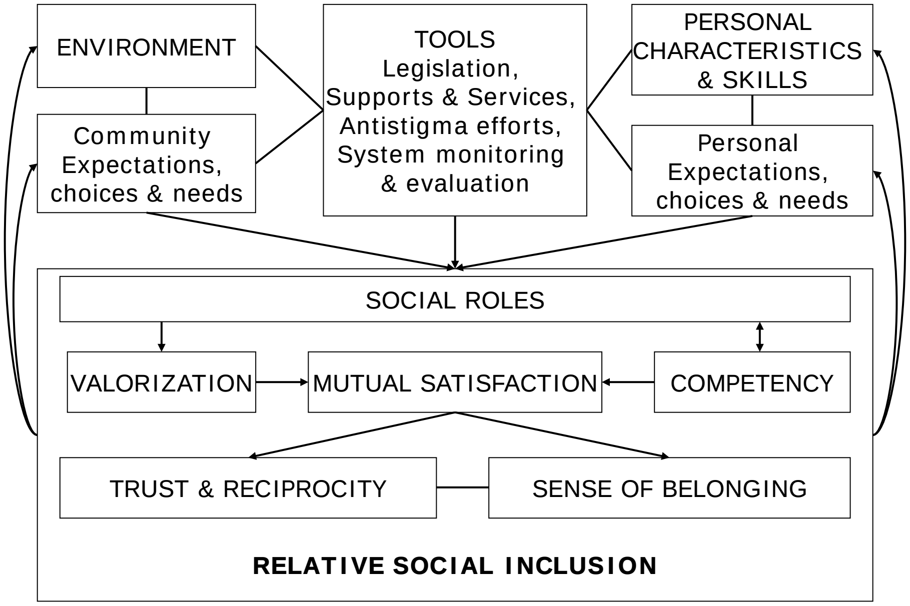

Figure 1. Model of relative social inclusion.

The degree of social inclusion one experiences at work depends on both the worker's ability to fulfil the job demands (*competency*) and the degree to which the work performed is perceived as meeting the needs of both the workplace and the worker (*valorization*). A good match between the two will yield mutual satisfaction. This satisfaction will also be secured by what we know as the "soft" features of employment: the ability to get along with others, to recognize others' needs and respond to them, and to know that effort is rewarded and recognized (*trust and reciprocity*), and workers sense that other workers know, value and respect them and subjective feelings of connectedness exist (*sense of belonging*). Work situations where inclusion is not achieved may be sustainable in the short term, but will not likely be satisfying or lead to strong quality of work life.

Challenges to inclusive employment

Success in the work role for persons in marginalized groups can be challenged at a variety of levels. One is in the area of personal characteristics and skills. Skill deficits surface in people with intellectual disabilities based on the nature and extent of their impairment and their ability to either find a suitable job match where the impairment is not a factor or compensate for the functional challenges the impairment presents (37). People in other historically marginalized groups may also lack basic skills, such as language barriers and social behaviour differences sometimes seen in new immigrants, or lack of training or education associated with historical opportunity gaps experienced by Aboriginal people, people with disabilities, or homeless people. Indeed, education level is inversely related to employment rates (38) and as such, those with low levels of education are at risk of falling into poverty.

Poverty itself becomes endemic, in part because people living in poverty can find it hard to connect to appropriate training and skills development (39) but also due to chronically lowered expectations due to stigma, self-stigma and repeated failure (40). It is hypothesized that people with strong social skills are most likely to succeed in employment (41,42) and thus people who are outside the "norm" due to cultural or interactional differences may lack personal characteristics that are valued in a particular setting. People in marginalized groups, even when employed, typically fall to the bottom of the employment "hierarchy" such that they earn low wages and fail to build sufficient skills and experience to move up into jobs that will move them out of poverty (5). The generic relevance of these facts stresses the importance of pooling knowledge and creative ideas across areas of disability, poverty, culture, and other known sources of marginalization.

The challenges marginalized individuals often experience relative to basic job skills impact *competency* for work, and even if jobs are found, job retention may be low due to failure to adequately *satisfy workplace demands* and *employers needs* based on deficient workplace skills and social behaviours, and lack of *personal satisfaction* that arises from the need to work beyond or below one's capacity and resulting feelings of inadequacy.

A number of *environmental factors* also challenge employment success. Economic theory explains the persistence of an unemployed and underemployed segment of society as a form of "market failure", along with associated problems of insufficient basic services such as education, healthcare and housing (20). The business environment can also be unfriendly to those who are not highly competitive, and trends such as workforce downsizing job enrichment (which includes such strategies as job rotation, information sharing, and teamwork may disadvantage workers with a limited skill set (43-45).

Ultimately, when there is a poor match between personal skills and characteristics relative to jobs favoured by a worker and the expectations and needs of employers, the employee is not likely to be valued and retained. Further, they are unlikely to develop reciprocal relationships with others in the workplace if their contributions are not valued. The following case example, constructed as a composite of several cases encountered in the authors' past research, demonstrates how the cycle of unemployment can be perpetuated, and why inclusion fails to be attained:

Jenna is a 26 year old woman with a mild intellectual disability who lives in a small town in a rural area of her province. She remained in high school until the age of 21 in a special education program. Having few family financial resources and no post-secondary education options, after leaving school she began seeking work with the help of family and friends, and was also assisted by a job development professional. She had a strong interest in working with children, enjoys doing arts and crafts, and is a people person. This led her to identifying a goal of finding work in the children's day care sector. After close to 16 months of unemployment she secured a job in a private day care centre where a family friend was the manager. Her job duties included preparing lunches and snacks for the children and cleaning the play areas. She was occasionally recruited to supervise the children while they played outdoors.

Jenna became frustrated at work due to her sense that she was doing the "dirty work" and not having much opportunity to work directly with the children. She was reprimanded on several occasions for missing areas in her cleaning, and for leaving children unattended outdoors. The other workers did not warm to Jenna, as they felt responsible for checking her work, and she seemed to shirk her duties while everyone else was busy. She began missing work on a weekly basis, largely due to her discontent with the work situation, and her sense that "no one there likes me" and "the boss picks on me". Jenna was fired from the job after 5 months due to poor performance and unreliable attendance. She later found a job as a fast food attendant in a local restaurant, but maintained the job for only 3 days due to her inability to keep up with orders during busy times of the day. She has been unemployed for the past 10 months.

In this example, we see a poor match between the worker's skills and the job requirements, and only partial alignment of the job with her aspirations. The job in the daycare centre failed to satisfy her needs to be liked and valued by others, to engage in creative activity, and feel valued. Her disinterest in this job and her lack of attention to detail resulted in an absence of satisfaction for both employee and employer, a situation that only became worse when she began to receive reprimands and no signs of respect or warmth from her co-workers and supervisor. Ultimately, after this job failed, she took a new job just because it was available. Again, she had a poor skills match, and was unsuccessful. Two failures led to persistent unemployment. With each month of unemployment, she is less likely to connect with another job. This leaves Jenna dependent on her parents and living at home. Her only recourse will be to apply for a disability benefit, which may reduce even further her likelihood of seeking permanent employment. Lack of a daily involvement outside the home, if she fails to become involved in other community activities or training, will begin to further isolate her. Her work situation and poor quality of work life and workplace inclusion thus have overflow implications for quality of life overall, threatening physical and psychological development, material and emotional well-being, dignity and respect and relations with her family.

We can use the model of social inclusion to understand barriers to employment role success for people in groups other than IDD. While the nature of the prevailing challenges may shift, analysis of a tenuous work situation in terms of the model components helps to identify where and why issues arise that result in failure to achieve satisfying employment outcomes, and ultimately a satisfying quality of life. For example, consider a new immigrant to an industrialized, Western economy:

Nasim is a 38 year old physician of Pakistani nationality who immigrated to Canada in 2009 in hopes of building a stable and secure future for his wife and two children. He left his family in Pakistan temporarily in order to establish himself in a job and find accommodation suitable for the four of them. He had an uncle living in Toronto, and a number of people from their home city of Lahore were living in the East York region of the city. He felt that these connections could help him integrate into Canadian life. Nasim is a Muslim, and is deeply connected to his religious and national roots. He speaks good but heavily accented English, having attended medical school at the Continental Medical College of Lahore.

Nasim was granted an immigrant visa on the strength of his professional training, and had a goal of obtaining a license to practice medicine in Canada within the next 5 years. He recognized the need to secure other forms of employment in the interim. With the help of his uncle, he found a job as a limousine driver with a company owned by Indo-Canadians. He had a limited period of training, in which he received an in-house orientation to the various districts and main arteries of the metropolitan area and was tutored in the rules of the road so that he could obtain driver's and chauffeur's licenses. He rode along with another driver for two weeks. In all, it took over 11 months for Nasim to become qualified as a limousine driver and to earn income. During this time, he became depressed and demoralized as he spent many hours alone, had very little money to live on, and became increasingly dependent on the charity of others. When he finally began driving on his own he was anxious much of the time due to his weak knowledge of the city, and the need to find efficient routes in the face of heavy traffic and confusing highway interchanges. He was surprised at how he was treated by many customers, who seemed to see him as a servant or technician. Many became irritated with him when he did not know how to get to a destination without lengthy consultation with his GPS system, and when they had trouble understanding his heavily accented English.

Nasim was accustomed to holding a highly respected position in society, and as a bookish, introverted man, was not particularly good at making general conversation. His medical specialty before immigrating was in anesthesiology, and his strengths were in precise measurement, attention to detail, clinical diagnosis and detailed documentation. In Canada, he was doing a job that required a high level of social interaction, navigational skills, and the ability to make quick decisions behind the wheel. He worked long hours due to his need to build a solid bank account, made no friends beyond the few acquaintances he met from his uncle's circle of friends, and had no leisure activities. The employer pressured him to work faster in order to transport more fares, and tips were low.

This case demonstrates the challenges to quality of life that can arise even for a very skilled individual when there is low congruence between one's skill set (*competencies*), personal preferences, and the requirements of the social role that one acquires. Nasim was not stimulated by the job, nor was he particularly good at it in the initial months. His *personal characteristics* were not a good match for the job, and although he successfully obtained the job and navigated the requirements of working with the help of his uncle and the employer, these *supports* were short lived, and he was left to fend for himself before achieving a level of *competency* adequate to satisfying customer needs. As such, his level of performance was not satisfying to Nasim, his customers or the employer. The *social role* was maintained due to an overiding *need* for stable income in order to attain the lifestyle of his dreams, and to become reunited with his wife and children. The work role ended up eclipsing any possibility of life balance due to his need to work long hours to satisfy key needs. Overall, although basic needs for existence were being met, QOL in this scenario could be judged to be poor, based on limited economic and emotional well-being, low social contact, and lack of inclusion in the larger society. Over time, it is possible that as his skills and comfort in the job improved, he would see better tips, feel more confident in conversing with customers, be respected by his employer, and hence achieve more satisfaction and better success in this social role. However, he would likely continue to find low job satisfaction when comparing this role with his preferred and better skill matched job of practicing medicine.

Addressing unemployment and underemployment

In cases of marginalization, whether due to issues of disability, culture, race, or poverty itself, the availability of effective “tools” is essential to breaking the cycle of exclusion and changing the relationship or fit between the different elements that lead to inclusion (34). These tools can take the form of policy or legislation that institutionalizes certain human rights, and provides guidance or structures for ensuring that they are met, or supports that help mitigate the impact of certain disadvantages. In the workplace, common tools are human rights legislation that mandate equal access to jobs, modifications to hiring and employment policies, specialized training that addresses individual language, cultural, or skill enhancement needs, or the provision of mentors, advocates or support persons. In our earlier example, a vocational support worker and appropriate policy might have made available an on-the-job apprenticeship whereby Jenna would be directly trained over an extended period to ensure a sound skill base; supports to help her connect socially with others in the workplace; a job coach to problem solve around challenges in performing certain tasks; and ongoing counselling to assist with career development. Some of these supports could have been developed from within the workplace if guidance and coaching of her supervisor had been available. People in social situations are often willing to accommodate others and be supportive, but lack the skills and knowledge to do so.

The willingness to integrate people from marginalized groups into a workplace often relates to the prevailing culture and attitudes espoused by an organization. Spataro (46) proposed a theory that organizational culture and attitudes towards diversity can be purposefully altered to change how organizations view themselves and treat others. She describes the cultures of differentiation - wherein the organization values and rewards certain characteristics that are consistent with their mission and way of functioning - and of unity – in which collectivism and identification with the company goals and direction supersede individual differences. A culture that differentiates between “us and them” is often characterized by stereotyping, categorization and exclusion. In contrast, a culture of unity is more likely to overlook differences, but fail to use them to competitive advantage. A “culture of integration” as described as one that values diversity, and moves beyond recognition and acceptance to a level of integrating different attitudes, perspectives and skills into the work life of the organization. This can be built through proactive workplace policy and positive supervisory leadership. Such actions would alter the environmental component of our model, and achieve heightened inclusion by helping incumbent workers value new workers of different backgrounds and with different personal strengths than their own. Such actions are critical to achieving perhaps the most elusive piece of inclusion – belonging.

Conclusion

For most, employment is a means to increased material and physical well-being, two core elements of QOL (7,9,18,47). For employment to contribute to the improvement of other key quality of life indicators, including emotional well-being and social inclusion, we must focus on employment as an opportunity to offer a valued contribution and a space of belonging (48).

Employment itself is a choice, as is the level of workplace inclusion that is desired and valued. Some people may not aspire to paid employment, and seek social integration through other venues where they can maximize critical aspects of the model, such as competency and mutual satisfaction, in a situation where workplace economics do not increase pressure to succeed or foster competition between peers (48). Such choices may contribute to improved inclusion in a variety of non-work contexts, but challenge quality of life in others (such as material well-being or living situation). Ultimately, individuals must make trade-offs between what is achievable and even desirable in given environments, and seek empowerment through knowledge of their rights and resources and solicitation of necessary supports to achieve the best quality of life possible, whether or not that includes paid employment. For most, however, a host of advantages result from employment, even at relatively low wages, and this must therefore be considered an important option. The challenge is to achieve a balance between the many factors that produce inclusive employment, and to ensure that effective tools and supports are available to those who need them.

Key Points

- Social inclusion is an integral part of Quality of Life
- Social role participation, including employment, is central to social inclusion.
- Social connectedness and sense of belonging are the ultimate outcomes of social inclusion.
- Enhancing one’s quality of life through employment is likely to be more successful in a holistic perspective where individual variability is taken into account.
- Providing adequate support and opportunities for is highly relevant in reaching social inclusion for each individual.
- Support networks are an essential part of efforts to achieve Quality of Life
- Social inclusion and employment are important in the development of self-image and empowerment

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The inclusive city through the lens of quality of life

Alice Schippers, PhD*[1]
and Lieke van Heumen, MS[2]
[1]Stichting Disability Studies in Nederland, Amersfoort, The Netherlands
[2]Institute on Disability and Human Development, University of Illinois at Chicago, United States of America

Abstract

In the city of Almere in the Netherlands, social policies are directed towards creating an inclusive society in which all citizens have the opportunities and resources necessary to participate fully in economic, social, and cultural activities that are considered the societal norm. Active citizenship, empowerment of persons with disabilities and partnerships between disability and mainstream organizations are the most important criteria for local practices in pursuit of this inclusive society. Social inclusion simultaneously incorporates multiple dimensions of the quality of life framework. This paper will discuss through the lens of the quality of life framework several inclusive policies and practices as they relate to employment, education, welfare and leisure in the city of Almere. Furthermore, the paper will describe how these policies and practices lead to a coherent program that contributes to valuable outcomes for persons with intellectual disabilities. Throughout the course of this paper the involvement of Almere's citizens with and without disabilities and the partnerships needed in realizing inclusion will be of particular interest.

Keywords: Quality of life, urban, social inclusion

Alex

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* ***Correspondence:*** PhD, Stichting Disability Studies in Nederland, Stadsring 2 3811 HR Amersfoort, the Netherlands. E-mail: alice.schippers@disabilitystudies.nl

This paper will refer to the story of Alex. Alex is a 27 year old performing artist and dancer. He was also born with Down syndrome. Alex has a creative and philosophical nature and is full of ideas and aspirations. His ambition is to become a famous citizen. He is well on his way towards reaching this goal. He has participated in several art exhibitions and performances. He was one of the actors in the popular Dutch soap series called ‘Downisty’. Alex lives in his own apartment in a building for young adults with disabilities and travels independently within the city limits. He uses a personal support budget to pay for his formal sources of support outside of his residence. He receives informal social support from his single mother and his brother. His mother refers to raising Alex as a life-changing event. She states as follows: ‘Society thinks that people with disabilities cost money.

That is true, but they also have a lot to offer. Alex enriched my life. Of course I also worry, because what will happen when I pass away? He is lucky to have a fantastic brother, who will hopefully take over my role’ (1).

Introduction

The concept of inclusion was first used and applied in the Nordic countries in the 1970s, referred to as ‘normalization’. Normalization aimed at the integration of services for persons with disabilities within the general service system (4). In the Netherlands normalization started after the Second World War with the establishing of group homes situated within local communities. This was a step forward from housing persons with disabilities in large segregated institutions. Since the 1980s further inclusive reforms have taken place in the Netherlands. Segregated residential settings, special education and sheltered employment were increasingly questioned. Social policy has since focused mostly on the realization of respite and short term supports as well as integrated living arrangements within local communities (5).

Foreign experts have criticized the Dutch deinstitutionalization process for not keeping up with the developments in other Western countries (6). The Netherlands is one of the few countries in which the number of people with intellectual disabilities living in institutional settings has grown since 1980 (6,7).

A similar development can be found in the area of employment. Since the 1980s sheltered workshops have had to compete on the mainstream market. The demands on employees increased and vulnerable groups started to be excluded from this type of employment, leading to the establishment of new segregated day activity centres. From 2011, policy reforms stipulated that sheltered employment will only be available for people who can under no circumstances be competitively employed (5). Additionally, inclusion of children with disabilities in primary education currently forms the core of social policy in the field of education.

Present Dutch disability policies and practices are directed towards realizing inclusion. Citizens with and without disabilities are entitled to participate fully in the community as well as to be included in employment, education, living arrangements and leisure time activities. The Dutch government has reinforced the rights of people with disabilities by signing and planning the ratification of the United Nations’ Convention on the Rights of Persons with Disabilities (UNCRPD)(2). Recent legislation reflects this commitment. The Participation Law (*Participatiewet*) that will come into force in 2014 promotes participation of people with disabilities in regular employment for example (3).

Despite these reforms, little attention has been paid to the promotion of social interactions between people with and without disabilities within the local communities (5). A concern is that the development of social interactions of persons with intellectual disabilities has been largely neglected. The social relations of persons with disabilities are often restricted to family members and professionals (5,8). Family relationships of people with intellectual disabilities are less complemented by stable and close friendships than in the general population (9-11). For adults with intellectual disabilities, interaction with the community is often regulated and controlled by professionals (12). The social relations at work in the sheltered workshop or the group home are not necessarily the ones that promote autonomy and self-esteem (13). Many persons with intellectual disabilities are in a ‘double-bind’ of marginalization, experiencing exclusion from and rejection and discrimination within the very social spaces that are the key markers of social inclusion policy (14).

Merely providing services in community-based settings is insufficient to ensure people's social inclusion within those communities. True social inclusion requires connection to others (15).The UNCRPD refers to full participation and inclusion as a general principle [art. 3], a general obligation [art. 4] and a right [art. 29 and 30]. This is an ultimate challenge within the Dutch context.

The term inclusion is commonly used in the field of disability policy, practice and research but has many different interpretations. The term is often used in a regular and nonchalant fashion. Diversity cannot be sufficiently incorporated and reflected in practices and policies when there is a lack of attention to the meaning and implications of inclusion for different individuals. Generalizations do not necessarily adequately represent the individual preferences of people with and without disabilities.

Alex prefers to spend his leisure time in an inclusive manner. His dance partner does not have a disability. However, Alex chooses to live together with other people with intellectual disabilities (1).

This paper uses Martin and Cobigo's (16) definition of social inclusion. These authors define the individual experience of social inclusion as 'complex interactions between personal and environmental factors, including social and cultural factors' (p. 277). Martin and Cobigo (16) state that discrimination, marginalization, and a sense of belonging to a community add to this understanding of inclusion. The authors include the six domains formulated by Hall (17) that are important to a person's social inclusion: (a) being accepted as an individual beyond the disability; (b) having significant and reciprocal personal relationships; (c) being involved in activities; (d) having employment; (e) having appropriate living accommodations; and (f) receiving formal and informal supports. Martin and Cobigo concluded that an understanding of what social inclusion means is needed for decision-makers and service providers to define the nature of their responsibilities, set actions, and assess their effectiveness in achieving inclusion. The goal to simply increase or promote social inclusion is not enough. Without an understanding of what social inclusion means, it is unclear what services and supports are aiming to achieve. Martin and Cobigo found that a person's perception of received social support is important in his or her experience of social inclusion (16). In this paper inclusion will be referred to as a concept that focuses on the perception of the person with a disability as well as the opportunities granted by and within society.

(Family) quality of life

In the field of intellectual and developmental disabilities inclusion and inclusive practices are important dimensions of individual and family quality of life. Individual quality of life has been studied for 30 years. The term can be understood as well-being experienced when a person's basic needs are met and when he or she has the opportunity to pursue and achieve goals in major life settings. Quality of life also refers to social well-being enjoyed by communities and society (18). More recently the concept of family quality of life has been developed. Family quality of life consists of interactions among family members, parenting, emotional well-being, physical and material well-being and disability related support (19,20). Quality of life is achieved when the needs of the family are satisfied and when the family has the ability to do what it values. Another important aspect of family quality of life is integration into the society so that family members can live, work, play, and have friends in the community. Family quality of life also entails family members' appreciation of the positive contribution individuals with disabilities make to their communities. Additionally, it seeks to have individuals with disabilities recognize their value to families and communities. This can help individuals with disabilities commit to the action of transforming their reality because empowerment must be forged *with them* and *not for them* (21).

Families are the main caregivers for individuals with intellectual disabilities throughout their lives (22). In order to improve the quality of life of persons with intellectual disabilities their family system needs to be supported as well (23). Additionally, many adults with intellectual disabilities are involved in the professional service system and are increasingly supported in and by the community. This means a wide range of stakeholders is involved in the lives of persons with intellectual disabilities. In the Dutch context it was found that opportunities for social inclusion can be created by developing sustainable partnerships among the different stakeholders who share responsibility for providing support. This is important because practice indicates that families with a member with a disability are often unable to independently improve their quality of life (24).

An integrating framework

The related concepts of individual and family quality of life as developed in the field of intellectual and developmental disabilities are also valuable in enabling the wider community. This notion will be illustrated while describing practices in the city of Almere. Ever since the concept of quality of life was introduced in the field of intellectual and developmental disabilities, it has been applied at multiple levels. A recently developed framework by Schalock and Verdugo (25) has been adapted by Schippers, Zuna and Brown to identify applications of quality of life concepts at the macro, meso and micro level (26). At the macro or system level societal values and attitudes as well as laws and policies have been addressed. The UNCRPD (2) is an example of the application of the concept of quality of life at the macro level. At the meso or organizational level services and support systems have been evaluated against quality of life outcomes. At the micro level, tools have been developed to assess a variety of aspects of the quality of life of individuals as well as families. Essential in achieving the ultimate goal of improving individual and family quality of life is for applications at these three levels to be interrelated. Connectedness between policies and practices on the system, organizational and individual levels can lead to more productive and effective outcomes for individuals and families (26).

The section below will discuss policies and practices in the city of Almere by applying the framework by Schippers, Zuna and Brown (26). At the macro or system level local policies will be addressed and at the meso or organizational level local practices. Additionally, the impact of these policies and practices on the micro or individual and family level will be described as found in a recent evaluation study by van Heumen and Schippers (27).

Policies and practices regarding social inclusion in the city of Almere

The city of Almere is an average-sized and relatively new municipality in the Netherlands near Amsterdam. The city currently has 195,000 inhabitants and this number is growing. In addition to being a recently established city, the inhabitants of Almere are also younger in comparison to the population of other Dutch cities. Currently, one-third of the population of Almere is under the age of 25 years and only nine percent of the population is 65 years of age or older (28). Local authorities and initiatives in the city of Almere are taking the lead nationally in implementing recently enacted legislation affecting social inclusion and participation of people with disabilities.

In the period of 2004 to 2006 nine families including a young adult with an intellectual disability were followed in the city of Almere. The families were individually supported by an intermediary in the realization of personal future plans. The main aim of this study by Schippers and van Boheemen (26) was to explore and describe positive practices by partners in supporting young adults with intellectual disabilities and their families in the development of quality of life. Two types of partnerships were the focus of the study: partnerships between families and service providers and partnerships within the health and community system. Results indicated the importance of these different partnerships. They added to the experience of quality of life and the competence in self-determination of the nine families.

Six years after the end of the study by Schippers and van Boheemen (26) a follow up study by van Heumen and Schippers (27) evaluated the presence and nature of long term effects of the original project on the quality of life of the adults with intellectual disabilities and their families as well as the sustainability of the established partnerships. This evaluation study focused on the perspectives of different stakeholders. The stakeholders included the adults with intellectual disabilities and their family members, support professionals, individuals in the wider social network of the families as well as other individuals in the local community. Inclusion and participation are relevant topics to both people with and without disabilities. The approach in this study enabled persons without disabilities in the community to be involved and participate in the discussions as well.

System level in the city of Almere: Values and views within policies

In 2007 the Social Support Act (*Wet Maatschappe lijke Ondersteuning*) was enacted in the Netherlands (29). This Act requires the inclusion of all citizens in Dutch society and the mainstreaming of services. In particular, it aims to improve accessibility of and access to services for all citizens. For example, it mandates municipalities to provide supports for older persons and people with disabilities such as transportation, wheelchairs and in-home modifications. The adoption of the Social Support Act has resulted in an important shift in the level of responsibility for inclusion from national government towards local authorities(26). The city of Almere has drafted several policies related to the life domains of employment, education and welfare in order to comply with the Social Support Act. For the effective implementation of these policies partnerships in the community between the system, organizational and individual levels become increasingly important.

Employment related policies have been formulated for persons with and without disabilities who have difficulties in the labor market. The association of local business owners, welfare partners as well as the local government anticipate a future shortage of employees and drafted a manifest called ‘Usingtalents’ (*Talentenbenutten*) (30). In this manifest the different partners promise to play an active role in securing appropriate employment for people. The partners aim to bring their corporate social responsibility into action by hiring people with a so called ‘work related disability’, which includes people with physical, psychiatric, intellectual and/or other disabilities.

Additionally, the local partners strive for students in secondary education to collaborate with local entrepreneurs in small projects. The term ‘co-makerships’ is used to describe these internships. These projects aim to promote social interactions, a diverse culture and a sense of social safety. Furthermore, the co-makerships aim to stimulate the development of local youth to become independent, self-directed and contributing citizens of the community (30). The aims of the co-makerships reflect important aspects of the concept of quality of life, namely self-direction, community involvement and social relationships for both people with and without disabilities.

Welfare policies are reflected in so called ‘vital neighborhoods’, neighborhoods in which the city together with local housing companies integrates social, cultural and safety projects (30). Examples of these initiatives are daily maintenance of public spaces to contribute to safety and the availability of sports facilities and after school programs in disadvantaged neighborhoods.

To bring the various policies into action, Almere’s local government initiated the application of the ‘Own Power Tool’ (*Eigen Kracht Wijzer*) (31). With this digital tool a person can direct him- or herself in finding needed formal support or funding to supplement his or her own natural and informal resources, including those to be mobilized by the social network. The ‘Own Power Tool’ covers all important life domains, including employment, education and living arrangements. Over 65% of consumers rated the use and recommendations of this instrument as positive (32). The tool proved to promote cost effective solutions, as it facilitates the support of a larger number of people with the same level of available resources (33).

Recently the local Welfare and Education department (*Dienst Maatschappelijke Ondersteuning*) together with the Windesheim University of Applied Sciences in Almere and Disability Studies in the Netherlands (DSiN) established a project called ‘The inclusive city’ (*De Inclusieve Stad*). The aim of this project is to integrate local inclusive initiatives in employment, education, support services and living arrangements in order to improve the quality of life of people with disabilities within an inclusive neighborhood (34).

The co-makerships and evaluation study by van Heumen and Schippers(27) are both part of the project ‘The inclusive city’.

Since 2009 Alex has been part of the so-called G-force panel (G-kracht panel, ‘G’ refers to Disability in Dutch) (35). The G-force panel has ten members with different disabilities and aims to positively influence local politics. The panel was installed by the Mayor of the city of Almere. Each year it formulates ten action points, which are then discussed with city council members. The action points influence local policies on issues related to safety and participation and impact local activities. They have for example resulted in the creation of a meeting forum for persons with autism.

The organizational level in the city of Almere: Policies put into practice

Several support service agencies in Almere aim to include people with disabilities in the areas of employment, education and living arrangements. An example of such an initiative is the Creative Motor (*De Creatieve Motor*), a cooperative of self-employed support workers. The Creative Motor employs the slogan 'Nobody needs to stand aside' (*Niemandhoeftaan de kanttestaan*). It aims to develop a new social infrastructure and to empower the capacities of all involved. This view aligns with national and local policies on mainstreaming employment for people with disabilities. The Creative Motor provides trajectories in which people with disabilities are trained and gain experience in mainstream work situations, for instance in the furniture industry. These trajectories then lead to internships or paid employment (36). Less integrated work situations are provided as well. 'Aunt Truus' (*TanteTruus*), a well-known pub in Almere, supports people with disabilities in employment. Despite its popularity the pub does not make a profit and is unable to pay regular wages to its personnel.

In the educational arena, Almere's citizens took the initiative to establish a local 'Academy for Independency' (*Academievoor Zelfstandigheid*) (37). The academy provides learning opportunities to people with disabilities to support their citizenshipas well as to enable them to develop to their full potential. Mainstream higher education often does not admit people with intellectual and other disabilities. This situation has led to the recent establishment of segregated educational initiatives. An example is 'The White Elephant' (De Witte Olifant), an arts academy for people with disabilities.

Several housing and support agencies provide services in Almere based on the principles of social inclusion. These agencies constructed apartment buildings where people with and without disabilities live together. Furthermore, they applied the principles of universal design (38).

People with disabilities and older people were very much involved in designing the neighborhood where Alex lives. Their involvement in the planning process resulted for instance in the placement of a bus stop close to Alex's apartment building. His older neighbors are also very pleased with this practical solution.

Inclusive leisure time activities are coordinated by the Abri Foundation (*Stichting Abri*), an active interest group for persons with intellectual disabilities. One of the foundation's numerous activities is a biweekly party for young adults with and without disabilities, aiming to promote mutual understanding and respect (1). This initiative has the potential to contribute to the quality of life of individuals with and without disabilities by promoting social well-being and reciprocal relationships.

The individual and family level in the city of Almere: impact on quality of life

a. Inclusive methods

The evaluation study by van Heumen and Schippers (27)will be described below in further detail. The study aimed to evaluate the lasting impact of the project in which nine families each including a young adult with an intellectual disability were individually supported by an intermediary in the realization of personal future plans. Fourth generation evaluation principles were used in this study (39). This approach to evaluation argues that all stakeholders, all people who are affected by the evaluation, have a right to place their claims, concerns and issues on the negotiating table. A claim is any assertion that a stakeholder may introduce that is favorable. A concern is any assertion that a stakeholder may introduce that is unfavorable about a situation. An issue is a state of affairs about which reasonable persons may disagree. The evaluator acts as a facilitator of the evaluation and negotiation process (40). The fourth generation evaluation method aims to be both educative and empowering (41). It has been argued that fourth generation evaluation is an appropriate methodology for supporting participation (40,42). This type of evaluation is co-operative, it is *'with'* people rather than *'on'* people (40).

Data collection consisted of semi-structured interviews with family members and adults with intellectual disabilities as well as of focus groups with both groups. During these interviews and focus groups claims, issues and concerns related to the transition of the person with intellectual disabilities into adulthood, the quality of life of this person and the family, as well as partnerships and community support were explored and negotiated (27). In addition, photo voice was used as an accessible strategy to actively engage the participants with intellectual disabilities in the research process. The last stage of the data collection consisted of a presentation of the photo voice project by the young adults with a disability at a public town hall meeting (43).

Photo voice provides a way to offer voice and gain the perspectives of people with intellectual disabilities on their own lives and has been found to be an interesting and enjoyable method to this population. The goals of using this methodology have been to enable the recording of and reflecting on problems of a group or community, to promote critical discussion of these problems, to generate collective knowledge of the problems through discussion of the photographs, and finally to take action to change the problems by reaching out to those who influence or make policy. Other than problems, positive experiences as well as desires can be captured using this methodology. An important element in the quality of life framework is the attention for positive experiences in addition to issues of concern. The photo stories can be a compelling argument to fuel the power of collective empowerment both for people with intellectual disabilities and for their families.

Three students of the Windesheim University of Applied Sciences assisted in the data collection for the photo voice portion of the study to fulfill the requirements of their co-makerships. Over the course of several weeks the students supported the young adults with taking pictures. Before the town hall meeting the young adults with disabilities were supported by the researchers and students in selecting the five pictures most meaningful to them in order to give them control over the way they would be represented. The young adults were asked to describe each picture. Furthermore they chose the color of the poster their pictures would be placed on and gave their poster a title that reflected what this product meant to them. The posters were presented by the young adults with intellectual disabilities at a public town hall meeting in the city of Almere. During this meeting different stakeholders including individuals with disabilities, families, policy makers, (self-)advocates, journalists, students, researchers, support professionals and other interested persons were enabled to share and negotiate their claims, concerns and issues regarding the inclusion of persons with disabilities in the city of Almere (27).

The evaluation study can be seen as an inclusive practice in itself as it aimed to improve the quality of life of people with disabilities and their families, to assist in their empowerment and to enable their active participation in society (27).

b. Perspectives of individuals, families and the community

During the evaluation study six adults with intellectual disabilities were individually interviewed and four of them were willing to participate in the focus group and the photo voice project. The four adults who participated in the entire project described each other as friends. They currently live in the same residential setting in Almere where are supported to live in their own apartments. All evaluated the project and their quality of life as mostly positive. They enjoyed working with the intermediary and described their working relationship as pleasant and effective. They were able to indicate in which plans for the future they had been successful and which dreams they had been able to realize. They also shared additional goals for the future. They were positive about their home, free time, friendships and work, and indicated they had changed certain activities as they did not meet their needs. The young adults also shared some less positive experiences. They are concerned about their safety in the city and experience inaccessibility and exclusion. For example, they indicated it is difficult for them to use the public transportation system as recent changes in ticketing have made the process of travelling more complicated for them. In the photo voice project the young adults chose to share the elements of their life most important to them, such as work, hobbies and positive experiences with others in the community (27).

Alex took pictures of his home, while going out to dance and while at work at the arts academy 'The White Elephant (De Witte Olifant). He gave his photo voice poster the title 'Journey around the world'. His favorite photo featured on the poster was one of his private restroom. Having his own restroom is meaningful to Alex. He took pride in sharing his experiences with the community during the town hall meeting. He enthusiastically and actively contributed to the discussions at this meeting (27).

Alex's favorite photo.

Eight family members of the young adults with intellectual disabilities were interviewed and seven of them participated in the focus group. The majority of these family members evaluated the project as having a positive impact on their quality of life. Family members were enabled to better advocate for the young adult with a disability as it supported them to think outside the box. They learned not to be discouraged by imposed restrictions and exclusion of their family member with a disability but to pursue unexplored pathways. Hence, positive effects on self-determination of these families could still be observed six years after the project. The family members also learned to incorporate the individual preferences of the person with a disability and to provide him or her opportunities to explore their own preferences instead of making decisions for him or her (27). This confirms the observation in the literature that they play an essential role in supporting the choice and decision-making of these youth (44). Additionally, family members indicated that the young adults with intellectual disabilities had become more independent throughout the transition process (27).

Family members indicated that the limited time span of the project was a concern to them. After their work with the intermediary discontinued, it was more difficult for them to receive the support they needed to keep moving forward in breaking barriers and exploring options for their family member with a disability. Even though they made positive claims about the residential setting of their family members with a disability, they also voiced concern about the quality of the professional support at the residential setting. They were particularly concerned about the bureaucracy and lack of individual attention for their family member. Despite the transition of the young adults with intellectual disabilities from the family home to life in a residential setting and receiving professional support on a daily basis, family members stayed very involved in the lives of these young adults and continued to provide informal support (27).

The evaluation study had an impact on the community. The three students of the Windesheim University of Applied Sciences had very limited interaction with persons with intellectual disabilities or exposure to the disability community in the city of Almere prior to the start of their co-makerships. During the course of the photo voice process the students got to know the young adults with intellectual disabilities and collaborated with them on a basis of mutual respect, equality and equity. These experiences have the potential to contribute to a sense of psychological and emotional well-being as important elements of quality of life in both the disabled and non-disabled communities.

The use of photo voice and the town hall meeting started a dialogue between stakeholders, added to community building and empowerment and also impacted the views of the general public towards the young adults. At the end of the town hall meeting the general public wrote quotes on a white board with their dreams for the Inclusive City. Examples of these quotes were: 'Do not talk about them, but with them', 'To experience is to become aware' and 'Let's open our front doors more often'. The town hall meeting put the topic of an Inclusive City on the agenda within the community and asked for a commitment to realizing inclusion across the community. It was found at the town hall meeting that connecting different independently operating initiatives aiming at inclusion and participation is of particular importance in the city of Almere in the future. Most of all, the promotion of interdependence and of social contact between individuals in the community was found to be crucial in promoting inclusion (27). Social inclusion and reciprocal relationships are of importance as domains within the quality of life framework.

Conclusion

In order to bring into force and comply with the Social Support Act (*Wet Maatschappelijke Ondersteuning*) the city of Almere is proactive in striving for optimal inclusion within its locality (29). The system level policies in the city of Almere reflect values based on the concept of inclusion. At the organizational level several practices that enable and support inclusion could be recognized. However, segregated practices as a ‘next best’ solution could also be identified. The interconnectedness of life domains at the system level supported by the Own Power Tool (*Eigen Kracht Wijzer*) (31) could not be identified effectively at the organizational level. This interconnectedness between life domains such as employment, education, welfare, living arrangements and leisure time activities is important. Perceived concern in one life domain impacts the perceived overall quality of life and combining support in more than one domain is likely to have greater impact on a family’s overall quality of life (45). The evaluation study resulted in a similar conclusion. For instance, families voiced concern about the quality of the professional support in the residential setting of the young adults with disabilities. This finding is in line with international literature as support from disability services is one of the domains with the lowest satisfaction of families with a person with intellectual and or developmental disabilities (45).

Interconnectedness is not only necessary within the system and organizational levels but also between these levels. A fruitful template in achieving this interconnectedness can be found in the framework to guide policy development and systems change by Schalock and Verdugo (25). This framework is built on the concepts of vertical and horizontal alignment, system-level processes, and organization-level practices. Application of this framework can structure the thinking and analytic activities of systems and organization-level personnel and can help them identify significant disconnects between and among system-level processes and organization-level practices (25).The alignment of policies and practices at and between the system and organizational levels in the city of Almere is needed in order to improve inclusion and to contribute to the quality of life of persons with disabilities and their families. Additionally, it is of importance to establish a cross disability and diversity perspective in inclusive practices as well as policies. A good example of this is the Own Power Tool (*Eigen Kracht Wijzer*), developed for use by all citizens regardless of their disability status to assess their needs for (in) formal support. A cross disability perspective is also valuable in creating inclusive employment and educational opportunities. These still tend to be segregated solutions. The pub Aunt Truus and the White Elephant Arts Academy are examples of segregated initiatives in Almere. An example of an integrated solution is that of students with intellectual and developmental disabilities taking part in mainstream education together with their non-disabled peers so they receive a meaningful high school diploma. Such a diploma better reflects their skills than an individualized education program (47).At the individual and family level the results of the evaluation study by van Heumen and Schippers (27) support personal future planning for young adults with intellectual disabilities and their families in the transition to adulthood. It enabled them to better articulate the lifelong support they need with regards to different life domains. Supported personal future planning led to long term outcomes as positive effects on self-determination of these families could still be observed six years after the project. Importantly, it was found that effective support needs to be family-oriented. A combination of supported personal future planning, family support and the application of the Own Power Tool (*Eigen Kracht Wijzer*) is recommended to strive for a long term positive impact on personal and family quality of life.

It was found in the evaluation study by van Heumen and Schippers (27) that using inclusive methods impacted social inclusion positively. During the photo voice project several requirements of social inclusion as mentioned by Martin and Cobigo (16) were met such as the active involvement of the adults with intellectual disabilities and their families and the reciprocal relationships they experienced. Working with the students in the photo voice project made the four adults with disabilities feel accepted as individuals beyond their disability. Photo voice emphasizes the importance of insider's perspectives on the lives of persons with disabilities. This perspective is important to tailor policy and programs to improve the quality of life of people with intellectual disabilities. Furthermore, the self-representation of the young adults with disabilities in the community at the town hall meeting empowered them and improved their self-esteem. It is important that community events and activities like this town hall meeting are made accessible to persons with intellectual disabilities by sharing information that is meaningful and understandable to them. In order to be successful in optimizing the quality of life of persons with intellectual disabilities and their families and to strive towards a society that is more inclusive, barriers to meaningful inclusion need to be removed. Enablers and facilitators in reaching these goals can be more powerful when they are interconnected within and between the systems', organizational and individual level.

Conclusion

In this paper several inclusive policies and practices in the city of Almere with the aim to create an inclusive society through the lens of quality of life were analyzed. These policies and practices and their interconnectedness within and between the system, organizational and individual level were discussed. Furthermore, the impact of these inclusive initiatives on the lives of persons with intellectual disabilities, their families and stakeholders in the wider community were addressed.

Important elements in enabling an inclusive society while positively impacting the quality of life of all persons involved are:

- The implementation of proactive policies that enable and support inclusion.
- The aim to interconnect policies and practices supporting people in different life domains at the system, organizational and individual and family levels.
- The use of inclusive methods as a powerful tool to empower and promote positive self-representation of people with disabilities.
- The application and implementation of personal future planning while including multiple stakeholders.
- The availability of family oriented support.
- The attention for the perspectives of multiple stakeholders in creating active meeting spaces to promote mutual understanding, reciprocal friendships, equality and respect.

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The cascading transition model: Easing the challenges of transition experienced by individuals with autism and their support staff

Nehama T Baum, PhD (Psych)[*1]
and Meaghan Edwards, BA (Hons)[2]
[1]MukiBaum Accessibility Foundation, Toronto, Canada
[2]The University of Sydney, Faculty of Medicine, Australia

Abstract

This paper describes the cascading transition model based on the multi focal approach blended with quality of life principles and values. The multi focal approach is a cohesive, humanistic, person centred, holistic, therapeutic approach. Believing in ability beyond disability, its purpose is to enhance the well-being of the person by opening a window of opportunity for the actualization of the person's potential. This positive, person centred, individualized approach forms the foundation for the development of educational, and treatment support programs. Although some of the material in this paper comes from research when available, most of the commentary part is based on clinical observations and experience. Application of quality of life principles developed in the field of intellectual and developmental disability (IDD) has been explored and related to the area of transition planning for individuals with complex autism, dual diagnosis and other developmental disabilities. Transitions for people with such challenges are difficult and can result in serious disruptions in their own lives, their families, support staff and others in their environment. In contrast to change, transition refers to a gradual move from one place, activity or situation to another. The framework of the cascading transition model acknowledges that transitions, both large and small, might be equally challenging to individuals with and without disabilities. Quality of life philosophy provides the framework for the exploration of the application of principles including choice, self-image, self-determination, empowerment and the role of emotional factors.

Keywords: Quality of life, transition, intellectual disability

Introduction

Quality of Life in the field of intellectual and developmental disabilities (IDD) is a well-developed concept and avenue of enquiry, and as Brown and Faragher (1) suggested, the concept of quality of life (QOL) over the last four decades has helped to

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[*] ***Correspondence:*** Nehama T Baum, PhD, CPsych, MukiBaum Accessibility Foundation, 401 Magnetic Drive, Unit 25, Toronto, Ontario, Canada M3J-3H9. E-mail: Nehama@mukibaumfoundation.com

promote a gradual change in our perception of individuals with IDD. Woodill et al (2) contend that QOL was not intended to be exclusionary, but that it must apply to all, including individuals who are challenged by disabilities. Approaches based on QOL must be capable of supporting and empowering interaction between individuals and their environment and include the belief and acceptance of the notion that individuals, regardless of their abilities and/or challenges have their own views about what constitutes quality of life for them.

The concept of QOL can now be considered not only as a theoretical academic topic, but as a concept with practical applications. Investigators such as Woodill et al (2), Renwick, Brown and Raphael (3) and Felce and Perry (4) suggested that in QOL it is crucial to integrate the principles of quality of life into practice. Professionals in the field of QOL are examining how we can utilize its basic principles to better the lives of people with all disabilities.

Brown and Faragher (1) iterated that QOL has come to include social well-being, holism, choice, personal control, perception, and self-image. The inclusion of such perceptual aspects in the definition of QOL has meant that it has become important to include both objective and subjective perspectives in our measuring tools. This shift in belief from a sole reliance upon traditional “objective” measurement techniques has given a voice to the internal aspects of the experiences, wishes, wants, opinions and choices of people with IDD. This has enabled the creation of a better balance between the internal subjective or perceptual aspects of QOL and the more external objective aspects. It is therefore possible to build a bridge between the rhetoric and the practice, and as demonstrated in Baum’s examination of the QOL of direct care staff, make the application of QOL principles and approach both feasible and useful in many situations and settings. As a result, key concepts and principles which developed in the field of developmental and intellectual disabilities can now be applied in a wide variety of contexts, and in very specific instances, as this book attests.

Brown and Faragher (1) emphasized that, for individuals with IDD, the application of QOL concepts to service support models can have a significant impact. An improvement in functioning may occur when an individual moves from a difficult, negative environment to a supportive environment guided by QOL principles. As they suggest, the positive environment can often have a limiting impact on any previous negative experiences. Their notion echoes Feuerstein’s (5,6), who was a pioneer in the field of rehabilitation of cognitive development of people with IDD. Feuerstein (5,6) argued that with a change in approach such as the provision of mediated learning experiences, remediation could and did occur. Feuerstein showed that with intentional mediated learning experiences, negative societal belief systems can be changed resulting in a more optimistic and encouraging environmental outlook and practice.

How important is the application of QOL principles to the creation of supportive and human environments?

A widening of the understanding of quality of life has emphasized the right of individuals with intellectual and developmental disabilities to become a part of, and live in the community rather than in institutions which for many years were the recommended solution of choice. One good example of the importance of applying QOL principles to real life situation is Felce’s (7) exploration of the impacts of moving from institutional to community based alternatives. He found that positive living environments further enhanced individuals’ QOL and increased chances of behavioural improvement. In this particular example, Felce explored and focused on changes in the life of individuals with severe intellectual disabilities. Felce noted that in spite of the variability of the methods used by him and by others, including those with similar transition situations, the outcomes in these projects suggested that similar conclusions could be drawn. For instance, discussing the specific example of a change in the type of accommodation, it became clear that even though it was important for people to live in smaller community houses, the house size alone without the application of QOL principles was not enough to guarantee a better life. More importantly, as Felce adds, a change in staff “hotel” attitudes is central to positively modifying the environment. Staff members have often continued to practice this attitude by taking care of all duties in the residences resulting in maintaining residents' dependency. Even after the move to a smaller home from an institution, staff practice of "hotel" attitudes is at times rationalized by them through expressions of belief that the "severity of the challenges" of this population makes them unable to acquire these necessary independent skills. Therefore, solely transitioning to a house in the community and even having regular staff support does not mean that the environment has transitioned from an institutional culture to a true quality of life community living culture. Felce adds that in addition to better housing and location, and having staff support, it is important to have three additional factors in providing meaningful transitional support to such severely affected populations. These are: available (and appropriate) activities, effective assistance and a high ratio of skilled staff supports. Baum (8) further emphasized that such change from a traditional care "hotel" model to a support QOL model creates opportunities for residents to fully participate in community life. It is crucial that staff and organizations understand that such accomplishment can only be achieved with the provision of opportunities for full participation and with acceptance of the fact that this is vital for creating a change in the culture in which people can come to live lives like others in the community.

The phenomenon of maintaining dependency was not exclusive to staff working in residences serving severely challenged populations as is in Felce's (7) example. This attitude can also be found in other residential schools and day programs serving children and adults with various types and levels of developmental and allied difficulties. Based on the framework of the multi focal approach, Baum created an eight months training course for residential staff titled: "Do not teach me helplessness, teach me ability" (8). This course was specifically developed to deal with a particular attitudinal problem practiced in a community based residential program serving high functioning individuals with varying levels and types of mental and developmental challenges. As Fishbein and Ajzen (9) explained, a point of view is expressed in an approach that is manifested in behavioural conduct, which in many transition situations deprives the residents of opportunities for developing ability but rather reinforces their helplessness. Residents did not have chances to become self-aware of their own being and ability and how to use their knowledge of practical day living skills. This specifically designed course was aimed at helping staff to continue with implementing the multi focal approach principles of ability functioning, to change their attitude and to apply the multi focal approach and QOL based principles.

Baum (8) found that without a change in the organization's values reflecting a change in culture and belief system, staff reverted back from their practice of the multi focal approach principles to their previous "hotel" care attitude. This phenomenon was not unique to that particular residence. It was also observed in various other congregated community homes and/or day programs even with different populations including those with dual diagnosis and other developmental disabilities, who were otherwise higher functioning, such as those with more established verbal and cognitive skills who were able to independently take care of most of tasks and activities.

Staff and organizations often seem to lack awareness of how the so called 'small things' were taking away ability independence opportunities from the people served resulted in reinforcing helplessness. This is a major concern in the application of a quality of life approach in which self-determination is emphasized. For example, when going to the supermarket, who holds the list of groceries? Who chooses the groceries? Who pays the cashier at the counter? Both staff and residents' answers confirmed that the residents from that particular home, all of whom were literate, and had money management skills, were only pushing the carts and obeying staff's instructions to bring specific items from the shelves. No resident got the opportunity to take part in creating the menu or the shopping list or to pay at the cashier. QOL principles emphasize that providing opportunities for choices and for independence are critical to enable people to take charge of their own lifestyle.

While Felce's (7) example dealt with residential transition, the following example deals with transitioning from adolescence to adulthood. Awareness of the transitional challenges faced by high school students has increased in the last few years. Many school boards developed projects that focused on the evaluation of the impact of transition interventions and implemented programs (10,11).

Some of the people in these examples have disabilities other than autism. However, due to their sensory difficulties a greater focus is put on the challenges individuals with autism face when change and transition occur.

Autism spectrum disorders

Based on diagnostic information gathered through practice, observations, and research data, it is already accepted that both nonverbal and verbal-able individuals, in spite of using different modes of communication, are significantly challenged in areas such as communication, social, interaction and relationships development.

Individuals with autism spectrum disorder (ASD), regardless of the level of their challenges seem to be highly sensitive to changes in their environment and find it challenging to transition from one situation or location to another. To cope with change and transition, persons with such challenges often become dependent on routines that seem to provide them with some sense of safety (DSM V- ASD Fact Sheet).

As a spectrum disorder, autism is considered to present a complex manifestation that is associated with both neuro-developmental and/or other health conditions (12-14).

As in other complex conditions, the various facets of autism have an impact on the person's emotional, social, language communication ability, and sensory neurological functioning (14). The multi focal therapeutic approach (15-17) takes into account the inner variability of such a manifestation. Thus, any support provided should be based on an individualized person-centred perspective that will properly answer the developmental, emotional and sensory needs of the individual. According to the multi focal approach it is imperative that close attention will be given to the systemic connectedness (12,14) between the constant interaction made between the 'where' and 'how' these various facets of autism manifest and dynamically relate to each other and how they interact, inter-relate, and trigger one another (12,18).

Communication difficulties pose a challenge for nonverbal persons who, unlike verbal-able individuals, revert to using substituted behavioural modes of communication. Grandin (19) remembers her "frustration of not being able to talk at age three" which caused her to communicate her frustration in temper-tantrum behaviour. Grandin's description of her experience creates a bridge of understanding between the scientific description of the characteristics of autism to the personal experience and voices of individuals and families affected by ASD. Such a link makes the non-personal science data relevant to our person-centred QOL orientation.

Through the sharing of such personal, first-hand experiences, a door is opened to the world of autism as it is personally experienced. It gives us an opportunity to expand our understanding of the many layered strands of autism and how each person affected can weave their own "fabric of autism" (18).

Similar to the behavioural mode of communication Grandin used when she was three years old, are used by other children and adults when they are faced with their inability to express themselves (20). One of the basic principles of the multi focal approach is a focus on learning to understand the behavioural communication language manifestations of both the verbal-able and non-verbal people served.

Very often, when referring to various aspects of the domains of the Family Quality of Life Survey (21), parents speak about the impact the disability of their son/daughter has on their FQOL. Other families express how happy and full of expectations they were when they first brought home their new born baby anticipating bonding with their "dream-child" only to have their happiness collapse when, a few months later, after what seemed to be their child's normal development, they hear the "dreaded" diagnosis of Autism (8,15). Here is the raw expression of a mother facing her daughter's challenges:

> "Kim was crying all the time after she was born and the doctor stated she was a colicky baby. Her crying day and night has not stopped even after six months. Kim was diagnosed with classic autism at 2 ½ yrs. old. At that time I began reading the only books available to me. Most of them referred to autism as 'abnormal psychology'. My daughter was broken and I wanted to fix her.….I realized that grief is something that every

parent who has a child with a disability has to come to terms with" (22).

Coming to terms with the loss of the "dream-child" regardless of the type of disability the child has, is a process in which parents have to face their feelings of guilt and grieving and work to resolve their pain, thus enabling them to accept their child, irrespective of what is often seen to be inconsistent and contradictory aspects of the child's autism (8,15). In discussing contradictions a person with autism manifests (14,18), Miller says: "There are good days and bad days … Kim appeared to be deaf at times and then again at other moments, she reacted to sounds".

In order to help parents understand such seemingly conflicting manifestations of the various elements of autism, there is a need to learn to understand each manifested element, measure it and make sense of how they work and interact with, and in contradiction to each other. Only then, she said, will parents be able to start recognizing the patterns and begin the "detection of the systemic nature of this puzzling disorder" (18). Miller (22) adds an additional dimension when she says that like many children with autism Kim had a habit of escaping, forcing Miller to continuously stand guard to ensure Kim would not run and harm herself or cause trouble. Other parents shared similar experiences.

Dawn Prince-Hughes (23,24) so poignantly describes how it feels to live with autism:

> "I was born with autism and always had sensory challenges that overwhelmed me…. It is easy to become exhausted when one is using one's energy at all times to build filters they weren't born with. It makes it difficult to interact with other people, difficult to understand culture, difficult just to get along in life" (24).

Challenges of transitions

Transitions are a part of life often experienced as a challenge by those with autism and other IDD. For those concerned with understanding the difficulties faced by this population, successful transitions throughout the lifespan, and indeed in everyday life, can be seen as essential to supporting individuals to live a life of quality. Transition is a time during which some change has occurred or is about to take place. A change is an event while transition is a change from the old to the new ideally characterized by a gradual, slow and smooth process to enable getting used to the new and letting go of the old.

It is usually believed that only people with problems like those faced by individuals with autism and/or other disabilities find transition and change to be overwhelming. The reality however is different. All of us have to go through transitions in our lives experiencing the stresses that change can trigger. From the moment of birth we are faced with the need to cope with and adjust to a new and different reality. After birth we transition from the protected warm environment of the womb to coping with gravitation, to adjusting to independent breathing, feeling air on our exposed skin and being in a world full of sounds and sensations. These are the first of many big and small transitions, we will continue to encounter in our lives. Growing up we continue to encounter additional transitions such as: our first day in nursery school, elementary school with its different environment, high school, the different collage culture and then facing again the big transition to adult life and its responsibilities.

Simultaneously with the changes our children experience, we, as parents, also have to go through our big and small transitions. The birth of our first child changes our lives forever. Being tied to constantly providing our new-born with all their needs is a reality in which we are totally focused on the responsibilities of being a parent which at times makes us feel that our QOL has changes since we have seemingly lost the freedom we previously enjoyed. The direction of such a relationship continues including our on-going focus on our children. Life changes again when our children, after going through the storms of adolescence become young adults claiming their autonomy and deciding to move out. Suddenly, we face transitioning from an identity of a provider of support to the new reality of our "empty nest". This newness involves accepting that the child/ adolescent is no longer dependent on us. We will have to adjust to the letting go of the previous direction of our relationship and acknowledge that the old parent/child relationship has moved to a new direction of adult to adult relationship. The successful completion of this transition will create a supportive and equitable family environment that will become the foundation of support when we face transitioning to old age. The following diagram illustrates this transition:

Parent → child/adolescent ↔ adolescent→
→son/daughter/ adult ↔ Adult/ (parent) →
→adult/son/daughter → old/parent

It should be emphasized that if change evokes stress even in individuals without disability, it definitely creates a big challenge for people with autism and other neuro-developmental conditions, IDD, and physical and/or mental illness. For individuals with ASD any environmental change seems to cause distress and anxiety often related to alteration of routines which impacts the person's ability to adjust and function. Sterling-Turner and Jordan (25) contend that transitions can be related to small things like leaving the house when going to transportation, or to larger, more complex transitions such as graduating or moving to a group home (26).

Moreover, it has been known for many years that unfamiliarity, whatever its form (change of classroom, teacher or instructor, and peers), produces a significant lowering of performance amongst people with disabilities, which can result in freezing behaviour, reduction in use of language, markedly reduced perceptual and motor behaviour, and in terms of duration may last for a considerable period of time (27,28). Clinical experience demonstrates that this is clearly shown in individuals with autism and therefore is likely to be a major issue in terms of transition from one environment to another as described in this chapter (25).

Examples of transitions issues

Stewart's (not his real name) moving to his new classroom felt like a very big transition. He adamantly refused to move! He was willing to stay in grade 4 rather than to move. Stewart explained that his new classroom did not have a green carpet. He was unable to accept the new environmental reality. Applying a QOL approach and, acknowledging the green carpet as a transitional object, we moved the carpet to the new classroom.

Like other individuals with autism, Kim also had problems transitioning from one activity to another. Holding something in her hand, served as a transitional object enabling her to move from activity to activity, "without tantrum or objection" (22).

Baum further explained that by establishing and internalizing a system of patterns people with such challenges are able to create a strong structured framework that provides a sense of safety and security (29). From a person-centred approach Rogers (30), recognized change and transition as the source of the challenges experienced by people with these difficulties. We need to accept these defenses and coping mechanisms as communication of the need for a well-designed transition process. Providing enough time and proper preparation for the transition process will ease the adjusting to, and coping with the new situations in both the physical and human domains. Some of the challenges during the adjustment period stem from what is involved in the process. Learning how to accept an interruption of regular routines and pre-planned familiar activities and schedules is difficult enough but breaking off the rigidity of the structure of patterns and possibly activate different patterns of behavior might be felt as more challenging. Flannery and Horner, (31) added that experiencing predictability might possibly reduce the stress caused by the transition.

The stress, anxiety and fear such changes bring, and the need to adjust (32, 33), require planning of the transition, and intentional mediation. Preparing individuals for the possibility of change and for how the environment will be altered is vital in enabling successful transitions (34). Using various sensory modalities in rehearsing the transition process is essential. Utilizing sensory tools during the process of the mediated preparation period will ease a possible encounter with unpredictability.

To be prepared for a change it might sometimes be sufficient to provide a person with information about a possible change in timing of events and in who and where it might take place (33). Because of the 'sensitive areas' of the top of her son Jeremy's head and mouth, Sicile-Kira (32) elaborated on the preparation she had to do before taking Jeremy to the dentist or haircutter. She further described the use of the scheduling method and the time span it required emphasizing that "if I forgot to put it on the schedule and to tell him in advance, I could get him into the car to go, but once we arrived, I could not get him out of the car" (32). Sicile-Kira further explained that it seemed that in order to mentally prepare himself for what might come and thus avoid facing unpredictability Jeremy needed to be informed of all the details of what was to come (32). In a later publication, she comments on the emotional aspects of transition. "Understanding the sensory aspect of their emotional responses is a great step toward helping them cope with new situations and experiences" (35).

The cascading transition model

As noted in any transition model, there is a need to recognize the importance of familiarity and the possible damaging impact of non-familiarity in the transition process. The cascading transition process ensures opportunities for familiarization will be provided on each level of the model. Many of the challenges spoken in the past had to do with the major impact unfamiliarity in new environment had on children's language and motor behaviours. Further, from a QOL perspective, the need for continuing familiarity to avoid the negative impact of unfamiliarity, including the opportunity to self-determine and a feeling of lack of control over one's own life can also be factors in resisting change (36). Frequently, individuals with Autism and other developmental difficulties have very little input into how their support programs are conducted and very little ownership over their environment. This lack of control may cause stress and emotional turmoil which is expressed in challenging behaviour.

The cascading transition program was designed to help mitigate the stress and its impact on the people who are transitioning. The elements of this transition plan were created to support both individuals with disability and their carers.

The transition involved an Adult Day Treatment Service (ADTS) that was relocating from a small, confined space to a much larger, specially designed building with features such as sound panels, skylights for natural light, colours chosen for their soothing properties, MDF supported walls for safety and high ceiling. Home rooms, vocational spaces, art studios, and computer rooms were established. Additionally, specialized dedicated rooms for various programs like drama, expressive arts, music, yoga, dance and movement were built. Fitness and gym facilities and multi-sensory and virtual reality facilities were also established to enhance health and well-being. This was an exciting time with many potentially positive changes, yet there was also a need to properly plan the transition process due to the challenges this population had in coping and adjusting to the "new". The cascading transition model presented opportunities for experiential involvement, increased familiarity, and as a result reduced stress, and thus eased the transition and supported self-confidence, and self-determination.

Planning for the transition of an adult program from one environment to another began approximately one year before the planned move to the new building. The strong relationship between stress and challenging behavioural communication necessitated careful planning and preparation aimed at alleviating stress and anxiety during the transition period thus empowering the people served and their staff. An important element of this model of transition was the inclusion of a cascading process which included senior management, supervisors, clinicians, front-line staff and the people served (see figure 1). Based on QOL principles and the belief that transition and change appear to be challenging to both individuals who do not have disabilities and people with disabilities, the cascading transition model was designed to utilize the skills and have the active involvement of all the participants whether disabled or not. Each participant had the opportunity to experience the implementation of QOL principles such as decision making, and some opportunities for self-determination. For this reason, the cascading process was developed for four groups: Management, supervisors including clinicians, front-line staff, and people served. Although the content was different for each group, the process and philosophy were the same.

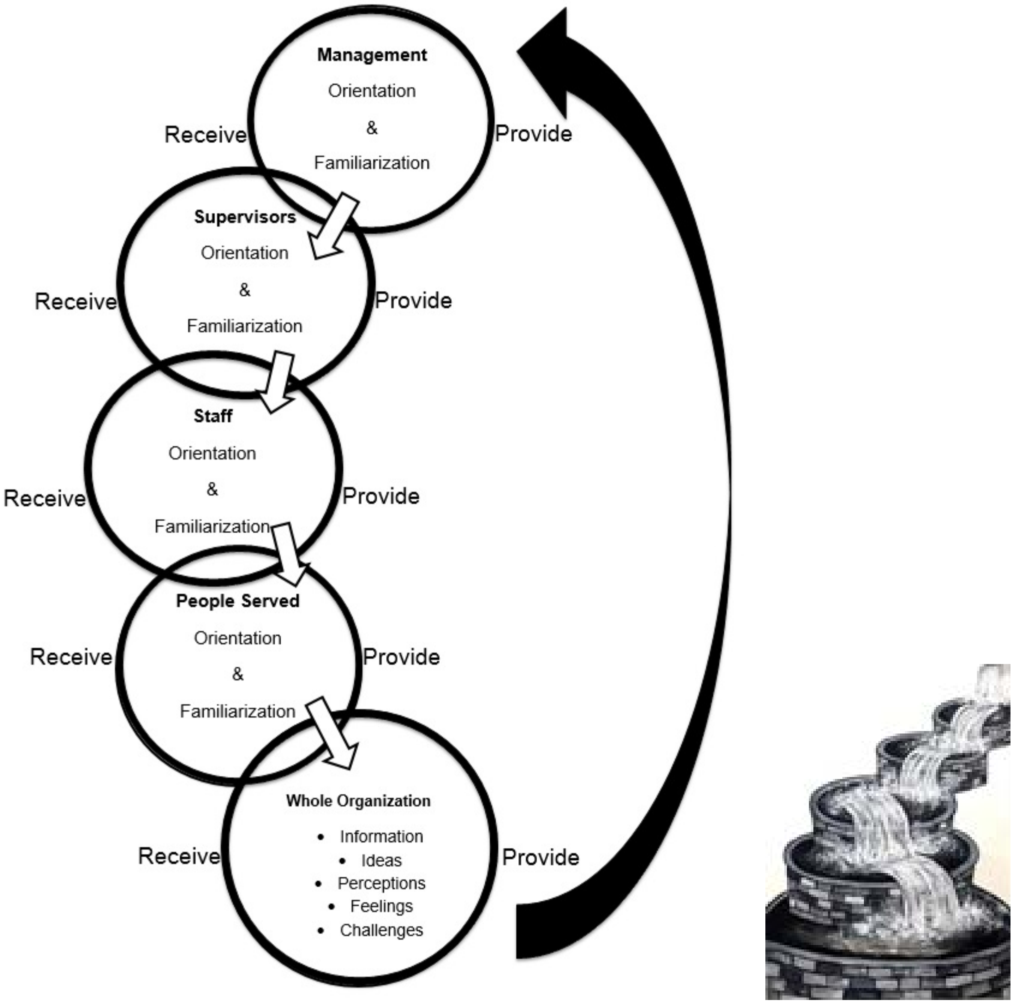

Figure 1. Cascading transition model.

The plan

The cascading transition was planned as a process with each step building on the previous one. A preparatory transition plan was created and carefully executed as the orientation and familiarization processes were cascading from each of the five levels to the next (see figure 1). While the content of the orientation and familiarization that each group experienced was unique to the level of responsibility, the dynamic of it was the same. Senior management was the first group to learn the particular concepts and structure of the environment and the rational of its design principals. After a verbal presentation, senior management visited the new building, had an opportunity to explore the building to become familiar with it and learn and understand the various design elements of it. This procedure prepared members of the senior management team to use this template in repeating the same process with the supervisors and clinicians who, through learning that orientation and familiarization process, were able to provide the same to the next level, the staff, who continued with the cascading movement by providing the same experience to the people served. As stated above, the content of each level of the “receive and provide” action changed from group to group throughout the cascading provision of information (figure1).

- **Cascading level one**: In their process, senior management learned about the conceptualization and reasons for dividing the building to four adjacent, but separate campuses: Sensory, art and vocational specialized programs, with a focus on the positive aspects and the possible impact of the structure on the programs, supervisors, staff and people served. Only after ensuring that members of the senior management team were clear in their understanding of the concepts and rationale for the design of the building, its structure and the new planning of conducting the programs, managers took the responsibility to provide the same process to the supervisors.

- **Cascading level two**: On that level, after learning about the building and its various elements, managers visited the building with the supervisors and clinicians enabling them to explore and become oriented with the large size of the space. Managers provided explanation of the particular concepts of the space and its special design elements. They discussed the location and area of each campus the supervisors were to be responsible for and the location of their offices that were embedded within their campus. Managers explained the rational and concept of why their personal offices were located in a central place in each campus. Supervisors also deliberated and discussed the opportunities such placement created for them enabling them to be available to their staff when needed, and provide them with guidance, support and direct involvement in the programs they supervise.
- **Cascading level three**: After receiving their orientation from their managers, supervisors went through the same process with their staff adding to the materials they have learned from their superiors the relevant additional contents, assignments and roles their staff needed to be exposed to, learn and assume. After their primary orientation and familiarization they visited the building guided by their supervisors. Staff was encouraged to visit the new building as many times they needed. In these visits staff members were able to explore their group rooms, learn the structure of their groups and explore possible changes in the staff composite that took place and the people that were to attend their groups. As part of this orientation and decision making process, staff were empowered to discuss their group program ideas and with the participation of the therapists, generate conceptions for and make decisions about the development of individualized treatment and support programs for the people served. Opportunities were given for input and choice making in an environment of conscious positive responses that enabled expression of feelings, inner stress and/or anxiety.
- **Cascading level four**: involved providing people served with orientation and familiarity of the “new place”. As part of the preparation for the transition and by taking into consideration the difficulties this population encounters when change takes place and transitioning occurs, the cascading transition process was designed so that the people served would be able to receive the most thorough, inclusive and comprehensive orientation process. In a gradual manner with much positive reinforcement, staff told the people served about the future move from the smaller building to the new larger place. For such an orientation process to succeed, the use of various visual and tactile sensory devices and cues as well as sensory-motor experiences had to be utilized (34,37).

These sensory aids were included in visiting the building where guided tours and explanations occurred. During the familiarization process people served had the opportunity to take “ownership” of their future “home” each in their own way in their own style of communication.

Accepting behaviour as communication necessitates letting go of the regular customary interpretation of such behaviours. Rather, it is important not to automatically judge the behaviour as aberrant even if it is thought to be an unusual acting out behaviour. It is essential to acknowledge the variability and difference of the behavioural communication and accept a different interpretation of the meaning and purpose of the behaviours (38, 39). Some individuals chose to tell stories and spoke about their goals for the new space. Everyone brought along at least one personal object. One, mostly non-verbal woman, claimed the space by running into each room and yelling once in a high pitched tone as if saying now I recognize this as mine. Another woman entered each room and spat on the floor, claiming the space as a part of her identity.

Other individuals used their own ways of asking questions and speaking with their staff about the place. In various future visits staff created programs conducted in their future group rooms and ran activities in common rooms such as the gym, art studio, drama and music rooms and in the cafeteria. In addition to these means of orientation and familiarization, staff also used stories about the move and processed the transition with illustrations and pictures chosen by the people served to represent the story of the building and the feelings around the move itself. Discussions with staff took place daily and the emotions of the people served were respected and considered whether expressed verbally or behaviourally.

In designing the cascading transition model, it was recognised that in order to be able to accept the ‘new’, one has to let go and say goodbye to the ‘old’. Through team participation, a “Moving to the new building and saying goodbye to the old” process was developed. This stage involved all people who were transitioning. Everyone went through a saying goodbye ritual at the old building. Art work was produced in which feelings and memories about the old building were expressed.

As the leading team of the transition process, it was important for the management team to first recognize their feelings about saying goodbye to the old space so that they will be able to provide support to staff and people served.

By understanding the meaning of transition and by feeling a sense of emotional closure they were able to provide support to staff and people serve to also get a sense of closure. This stage was an emotional one for all.

It was also an extremely important goal that all levels of staff could also create for themselves a sense of ownership of the new space. It is recognized that with a sense of ownership comes comfort, familiarity and confidence. A concrete schedule of this aspect of the transition was created. All levels of the staff team visited the building and began creating a sense of ownership by bringing to the new space key personal items such as photographs and objects of personal importance. Spaces such as offices and therapy rooms got names placed on the doors. Group meetings took place in the rooms assigned to specific teams. Key items where brought by staff to the new space expressing ownership over their own physical space.

Guided by the principle of self-determination, an important part of creating a sense of ownership and of accepting the “new home” was to begin getting involved in developing the vision for the space and the programs within it. At this stage the visions for the new space became fully realized. Concrete ideas were put in place and detailed group and individualized program plans created in order to maximize quality of life for the people served.

Working together, the staff team initiated and developed strategic plans for the building, with the idea that the new space would open up new possibilities for achieving goals and actualizing potential. Some examples included dedicated training spaces for staff, more targeted vocational training for the people served, and opportunities to allow all individuals to pursue goals in a warm and welcoming atmosphere. Further, staff developed their own visions in small groups which included planning of daily programming for the people served responding to specific needs by utilizing the new environment to its greatest advantage.

Some examples included creating a café run by the people served and lessening the need for negative behavioural communication by creating safe spaces for those people who might be overwhelmed by elements in the environment. This was a chance to voice ideas, to have opportunity for self-determination and choice making for expressing needs and for development of their own goals. In a group format, through discussions, art work, stories and visioning, a large poster was created showing painted feet of all participants representing the move from the old building to the new building, materialized with pictures of desired activities to happen in the new building.

Settling into the new building

Once the move was made and the physical transition was completed there was a need to continue attending to the emotional aspects of the move. Another ceremony was held, this time in the new building in order to welcome the new experiences and allow all involved to feel ownership over the new surroundings. Art work completed at the closure of the old building was hung on the walls of the new building, welcoming visitors, staff and people served.

Figure 2. Wall of strength.

An important part of the Cascading Transition Process was the concretization of the new "after transition" reality. Management held several meetings in order to strategize supports that might be needed around potential stress and anxiety from both staff and people served due to the change in routine.

Programs within the building were planned carefully to provide a measure of continuity while introducing the novel elements decided upon earlier. An example of such intervention was the use of the virtual reality room which was gradually introduced into programming, with staff being trained and encouraged to explore the room until a sense of familiarity was established. Staff held meetings within their smaller groups and reviewed how the transition was going. During this time support to people served and staff was given by encouraging discussion and responding to choices and communication in a positive manner. Moreover, people served became involved in concretizing their space by decorating it with new, as well as familiar items. They were provided with supports when attempting to develop new patterns and connections and were encouraged to discuss with staff and peers any anxieties and difficulties they felt. Staff were guided and trained to relate to behavioural expressions of stress and challenges responding to it in a positive and supportive manner. The last level of the cascading transition process (figure 1) presents a feedback loop closing the cascading process by taking it to the beginning level of the cascade. The content of this level portrays the practice of the QOL principles of, respect, valuing equality, choice making and inclusion of people with disabilities by expecting their participation in providing, on their level, the content for the same role of receiving and providing.

Research

Seventy-two people were served by the ADTS's three treatment programs in the sensory, art and vocational campuses. All had complex autism and other intellectual/ developmental, psychological and behavioural challenges.

A parallel research program was conducted to assess the transition process and the impact of the new building on the quality of lives of the participants and their staff, exploring whether a possible negative impact of transition (stress and anxiety) could be minimized and positive impact maximized, when both the transition to the new environment and the environment itself were designed to meet the needs of the participants. The researchers included a clinical psychologist, a researcher, a chiropractic and occupational therapists. Assessments were carried out at three points: pre-transition (May 2008 baseline), post-transition 1 (after the relocation/transition, August 2008) and post-transition 2 (looking at effects of the new building and the transition itself 10 month later, April 2009). At all stages, a standardized behavioural assessment, both proxy and individual were administered. The instruments used were: the Adaptive Behaviour Scale Residential and Community (ABS RC2), and a Quality of Life Environmental Impact Questionnaire (QOLEIQ) (40).

Quality of life (QOL) for individuals with IDD has been an area of concern for researchers and practitioners over recent decades, since the move towards deinstitutionalization and individualized service delivery (42,43). The QOL concept includes a life span perspective in which the promotion of quality of life for people with IDD relates to core ideas and includes key domains (43). This has become a critical issue for development, implementation and evaluation of support services. In addition to domains such as material well-being and physical well-being, QOL also expanded to include personal development, emotional well-being, interpersonal relationships, self-determination and choice. These domains became fundamental elements of the cascading transition model.

The QOLEIQ was created to evaluate the impact of the transition. The questionnaire focused on areas related to both the physical environment and the emotional domains. The QOLEIQ was created and formulated by the research team and tested for its reliability parameters. The test-retest method was used with a group of 30 support staff who were asked to fill out the questionnaire in the morning on behalf of two of the people with IDD served at the centre. Each staff member had a partner staff member who independently filled out the questionnaire for the same two people. The staff went away for lunch and participated in an offsite recreational activity and were called back in the afternoon. Once they returned they filled out the assessments for the same people as they had in the morning. In this way each person served had four questionnaires filled out by proxy: one from each partner staff member in the morning and one from each partner staff member in the afternoon. The tests were compared for inter- and intra- rater reliability. Over 80% agreement in both inter- and intra- reliability was found. For a copy of the questionnaire contact the author.

The QOLEIQ had two parts: A – Quality of life domains and B – Impact of the environment. Part A included health, friends, family, enjoyment, thoughts and feelings, and choice. These questions included yes/no choices along with space for qualitative information and comments. Part B included sensory impressions of the environment (noise, sounds, smells, colour of walls, space light, etc.) and emotions experienced in the environment (happiness, anxiety, anger etc.). These questions were answered using a Likert scale (always, sometimes, never). The questionnaire was administered at the three time intervals of testing to both the people served and staff as a proxy to the people they worked closely with.

A proxy assessment was completed by the staff for the individuals from each of the three programs (vocational, art and sensory). People who were able to communicate verbally filled out their own questionnaire independently or with the aid of a researcher/ interviewer. Attempts to interview individuals who were non-verbal by utilizing alternative means of communication did not succeed due to the complex challenging manifestation of their disabilities. The members of the research team were trained prior to commencing the interviews.

The ABS:RC2 and the QOLEIQ self-perception were administered through an interview with the individual and a proxy person most familiar with the person being assessed. It was hypothesized that results would give insight into the impact of the transition. The goal was to evaluate, both quantitatively and qualitatively, the functional skills, abilities and coping behaviour within the natural and social demands of the individuals' environment. We were interested qualitatively in exploring personal and community self-sufficiency, ability to personally and socially adjust and the possible impact the change might have on self-determination and responsibility taking.

It is important to realize that the results of the evaluation of the transition are in the initial stages of analysis but it is interesting to note that on average the scores of the various measures did not go down when environments were changed, as would be expected, but remained very similar and on some measures, increased slightly. There is also some evidence that there was considerable individual variability perhaps suggesting some individuals were affected more positively than others.

Our findings

For the purposes of this paper, we have mainly focused on the exploration and elaboration of the results from a qualitative, rather than statistical point of view. It is important to emphasize that approaching measured outcomes from a QOL perspective enabled us to reveal important aspects that enhanced our knowledge and understanding of the experiences of the people served but most importantly educated us about how these individuals perceived themselves before and after transition. Moreover, this focus helped uncover the degree to which staff knew the person they individually supported. Contradictions were found in answers given by the individuals when compared with staff's proxy responses. This brought to light the very important issue of questioning the relative merits of personal and proxy responses.

It was decided to focus on qualitative comparison between the transcripts of both proxy and individual responses with the idea that this focus can provide specific information about the specific issues raised by the people served and about the ways staff perceived and know the people they supported. Following are a few examples of transcripts illustrating similarity and contradictions between proxy and individual responses.

T.P: Individual Response	**T.P: Staff Response**
(Test II): "Does not know of any health problems concerning T.P."	(Test II): "Does not know of any health problems concerning T.P."
(Test III) Says she is "not healthy because she is old and worse than another peer". "does worry about things"; "does not think she makes good decisions"; "finds change hard to accept"; "like to try new things": "life isn't very good"; "people treat her as an adult because she is almost 60"; "feels she is in control of her life".	(Test III) "Is in good health and enjoys active things such as walks, horseback riding and exercises." "does not seem to worry about things "; "makes good decisions"; "transitions easily between activities and programs"; "does not like to try new things"; "is treated like and adult and gets opportunities and choices".

Contradictions in the health questions existed between proxy and individual responses in both tests II & III. These contradictory examples raise questions regarding whether it implied limitations to the person-centred approach in supporting the person served. Additionally a question about how much staff's lack of knowledge of the person served had an impact on the program and supports received.

S.B: Individual Response	**S.B: Staff Response**
Test II Says she " worries about moving [she says] the new building is a little stressful [and that she is] sad to move"	Test II She "worries about new experiences such as new contracts but does have confidence in herself"; "finds it difficult to cope with change"; "she will try new things but with encouragement".
Test III She says she "doesn't really worry about things but thinks she makes good decisions"	Test III She "does worry about certain peers in the day program attacking her"; "requires assurance when there is change so that she can cope with it"; "needs prompting to try new things".

Staff maintained the opinion that S.B. is worried while S.B. progressed from her response in test II, where she said she was worried about moving to the new building, to stating in test III that she does not worry about things. This contradiction reinforces the phenomenon seen in TO's example suggesting the possibility that even though some change in self-perception occurred for SB, who had 10 months of experiencing the new building, staff did not register this aspect.

H.C: Individual Response	**H.C: Staff Response**
Test I She "finds it difficult to adapt to change"	Test I Staff says she "finds it hard to adjust to change. The size of the new building was a concern for her".
Test II She "finds it difficult to adapt to change"; likes trying new things such as new contracts".	Test II Staff says "she finds it hard to adjust to change; the size of the new building was a concern for her". "Likes to try new activities".
Test III Stated that "she copes well with changes as they are a part of life".	Test III Staff stated that "she adjusts easily to change and will try new activities".

In HC's example, staff and HC were cohesive in their responses. Both staff and HC expressed similar perceptions in both the challenges and the change that occurred particularly in the attitude to change and the move/ transition to the new building. It is suggested that the time gap of ten months between tests II & III gave the opportunity to both to adjust to the transition and to the new building.

As predicted, the attitude of the people served to change was an issue that was central during the transition process affirming that change and transition posed great challenges to individuals with disabilities. Furthermore, as seen in the proxy transcripts, change and transition also captured a central place in staff responses, some of which seemed to be projections of their own feelings about change and transition.

J.V: Individual Response	**J.V: Staff Response**
Test I: Said "I worry about disrespecting someone and I feel bad about stuff I have done in the past"	Test I: Responding to the questions about change, staff said they believe: "he does not cope well with change [but] he is open to the idea of trying new things"
	Test II: Staff believe "he does not cope well with change"
Test III: "I think I am usually in bad mood but I want to learn to control my anger, this is against what staff feels" "I can cope with change fine and I like to try out new things, i.e. clothes"	Test III: "He likes his schedule and can find it difficult to cope with change. He does not like to try out new things"

This transcript reveals contradiction in staff, who in all three tests maintained the perception that J.V. is challenged by change. J.V. did not respond in test I to the worry and change items answering only a couple of questions. He chose not to be interviewed in test II but fully cooperated in test III. Comparing J.V.'s answer about attitude to change with proxy response of staff, possibly suggests that staff's perception might have been based on their past experiences with J.V.'s rigidity and reluctance to change and his refusal to try new things. Can it be that staff was not even open to consider the possibility of change in J.V's position?

As compared to other issues explored in the QOLEIQ it is not surprising that the issues of change and health captured a central place manifested in a higher number of contradictions and similarities than in other issues. Issues of self-perception, self-worth, and dealing with choice making were also referred to by the people served. An important feelings motif expressed in people's responses focused on the way staff treated and related to them. Through expressing their own thoughts and perceptions they had also revealed bits of their personal stories. It should be stressed how vital it is that we understand the subtext of the messages given by the people served. By developing sensitivity to and by validating the hidden meaning of the words, we would be able to understand the needs and wishes expressed and better develop and implement person- centered individualized programs based on the multi focal approach and quality of life principles. The following examples taken from the transcripts of a few of the people solidified the matters discussed above.

In her responses, J.M.'s life experiences were echoed when she said: "I hate my medication". "Staff decides for me what to do and only asks me what I would like to drink". "I do not feel I have a choice with respect to my emotions". Staff said: she is "fixated on these things [coffee break, lunch]… and cannot focus on other tasks [suggesting that, "she would benefit from programming at the centre which may provide her with avenues to try new things". J.M. was talking about not having a voice or opportunities for choice making and for self- determination while staff had their own agenda of how her life should be. Expressing a sense of not being accepted for who she is, D.D. said: "at the day program I get treated like a baby" while staff stated that she "is related to as an adult as she works independently".

An additional example can be seen in the opinion and ideas expressed by a staff in Test I about how to relate to P.Z. through a person centred approach: "Sometime staff through their tone make P.Z. feel that a small mistake was a big one"... continuing to suggest " empowering P.Z. through giving her responsibility and choices can improve her life".

When practising QOL principles, the issue of who is "right" would not matter. Respect and acceptance must be given to the perceptions, needs and wishes the person expresses. To succeed in practising and applying support programs according to QOL principles it is essential that staff will be trained and learn how to listen to the meaning beyond the words.

Conclusion

The people served who participated in the transition process came from three different population groups of functional ability within the ADTS. They were all severely challenged, making the transition process a needed and even complex project. It is essentially in a design and pilot stage and illustrates how aspects of quality of life can be built into such a process. The Cascading Transition Model emerged from the philosophy of, and was based on the multi focal approach (15) with an emphasis on individualized Person Centred approach and principles of QOL (45,46) which created a framework within which tools were provided for the development and implementation of appropriate support programs for each group and the individuals within them. An important QOL principle is that of accepting in a non-judgemental way the variability of all persons regardless of ability and level of functioning. Such respectful acknowledgment of the uniqueness of the person enabled more sensitive detection of the differences and individualism of each person in each population group.

The cascading transition process took into consideration that change might be challenging for both people served and their staff. The cascading model involved all persons in the centre each team on their own cascading level in which each person had opportunities to both receive and provide thus helping and being supported by their successive level (see figure 1). The cascading transition year long process provided the people served with the necessary time to accept and adjust to the idea of the change and mostly overcome their reluctance to move.

The variability of the challenges of the people served and the irregularity of not having the same staff in the same groups affected the quantitative outcome of the research. At the same time, exploring the narratives provided by both the individuals and their staff both clinically and academically provided a wealth of information that can be used for program development within a QOL orientation. It is suggested that in future applications of the cascading principle staff will have a more intensive training opportunity for a deeper acquisition of QOL and multi focal philosophies. The approach raises ideas and suggestions that might well be considered in building a variety of transition processes for a wide variety of people, both children and adults with or without disabilities.

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Vision impairment and quality of life

Paul M Ajuwon, BS, MS, PhD*[1], and Ruth Bieber, BSW, MEd(Rehab), RSW[2]
[1]Department of Counseling, Leadership and Special Education, Missouri State University, Springfield, MO 65897, United States of America
[2]Creative Consultant, Play With Perspective Ltd, Calgary, Alberta, Canada

Abstract

This paper discusses practical applications of the principles of quality of life (QOL) and family quality of life (FQOL) as tools for improving the well-being and satisfaction of people who have vision impairment and their families. The authors draw from authentic personal and professional experiences to illustrate the power of consumer choice and empowerment, the roles of perception, self-image, personal values, and human rights. Special emphasis is given to the power and impact of the dramatic arts for people who are blind and vision impaired. We analyse available findings that point to over 90% of persons with blindness or partial sight in low-income countries where most of them are considerably disempowered and excluded from community-based activities. Recommendations are advanced for policy-makers and frontline staff to infuse into their programmes practical strategies for needs assessment, inclusive education, work opportunities, and community integration of their citizens who have vision impairment.

Keywords: Quality of life, vision, impairment

Introduction

Vision impairment (i.e., total blindness or partial sight) occurs in every society throughout the world, and has done so for many centuries. Several writers in different cultures and different historical epochs have documented the attitudes and reactions of persons who are sighted towards individuals with vision difficulties (1, 2). Typically, such reactions included: shame, prejudice, discrimination and exclusion from community life, which tended to leave most persons with blindness in extreme poverty and dependency. However, from available writings of other scholars, it was not all animosity towards persons with blindness or partial sight, as the sighted learned to embrace and, even in some instances, admired the talents possessed by persons who had vision loss. Among those people who were blind who gained historical prominence were Homer, Prince Hitoyasu, Abdu'l Ala Al Ma'arri,

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* ***Correspondence:*** Paul M Ajuwon, PhD, Department of Counseling, Leadership and Special Education, Missouri State University, Springfield, MO 65897, United States. E-mail: paulajuwon@missouristate.edu

John Milton, Nicholas Saunderson, and Maria Theresa von Paradis (2,3). These individuals rose above the challenges of blindness to become famous, while the majority of their blind peers were frequently looked upon as practically useless, and some were at times given over for destruction (3).

In this paper, we discuss the twin concepts of quality of life (QOL) and family quality of life (FQOL) that are increasingly being used to enhance the lives of people with intellectual and developmental disabilities, and elaborate on the practical application of both concepts as tools for understanding the multiple needs and wants of individuals with vision impairment around the world. The thesis is advanced that the quality of life principles have become an important approach to support and implement interventions, while family quality of life connotes a logical extension to the concept of quality of life from the perspectives of family members and consumers (4).

More specifically, we reflect on several important and thought-provoking questions: Why is blindness such a dreaded disability, especially amongst some communities in low-income countries? What is the current situation of people with vision impairment in the world? How is society providing for the education, rehabilitation, employment, recreation, socialization, and creativity of these individuals who constitute a growing number of persons with disabilities, in spite of medical advances? How does poverty impact vision impairment, especially amongst people in low-income countries? How are families of these individuals coping with their children who have vision problems? Are adults who experience sudden vision loss being assisted with counseling and other rehabilitative measures to develop their creative expression and to re-integrate into family and/or work situations?

Furthermore, do professionals recognize the importance of individual thinking and learning that should ultimately lead to empowerment and choice of these consumers with vision problems? What intervention strategies have been put in place to ensure that people with vision impairment worldwide enjoy a quality of life and human rights comparable to that of their seeing counterparts?

In answering the preceding questions, the first author, Paul M Ajuwon (PMA) draws from his personal and professional experiences as an individual who grew up in a developing country and became blind as a child, and has lived and worked in both developing and developed parts of the world. Today, he primarily teaches at an American university, where he also conducts research into needs-based, disability issues in America and Africa. The second author, Ruth Bieber (RB) is a creative arts consultant who is legally blind and has lived and worked in Europe and North America. We showcase her work and research on creativity and the blind. In particular, we elaborate on the elements of the power of creativity to reflect the more developed state of the art currently being practiced. In contributing our perspectives to this publication, we posit that issues of human rights for persons with vision impairment transcend ages and stages of life for all members of society.

A global perspective

According to the World Health Organization (5), there are 285 million people with vision loss in the world today, of which 39 million are blind and 246 million have partial sight. The low- and middle-income countries of Africa, Latin America, the Middle East, and Asia, are where 90% of vision loss occurs, caused by cataract, trachoma, childhood blindness, onchocerciasis (river blindness) and refractive errors (6). Foster (7) estimated that between 50-75% of all blindness is either preventable or treatable with currently available technology. The magnitude of vision problem is better understood when we acknowledge the fact that vision is a dominant sense. Indeed, psychologists have long established the fact that eighty to eighty five percent of an individual’s perception, learning, cognition and activities are mediated through vision (8). This underscores the pervasive problem associated with the inability of developing countries to control or manage the disability conditions within their populations.

Less than two percent of children and youth with vision impairment in low-income countries have access to any form of education or training (9). This lack of access poses a formidable challenge to the overall efforts to improve the conditions of the estimated 1.4 million blind children in the world today (10). These children have a lifetime of blindness ahead, which impacts their opportunities for education, employment, recreation, and earning potential. It is well-known that early onset of blindness negatively affects psychomotor, social, and emotional development. Furthermore, blind children have a higher death rate than their sighted counterparts, and in developing countries, up to 60% of children are thought to die within a year of becoming blind (11).

Serious concerns have also been raised with the world's ageing population (12). With a threefold increase in blindness for each decade of life, the blind and vision impaired are becoming elderly (6,12). In fact, it has been projected that by 2020 there could be up to 100 million people with blindness, with the majority of them in developing countries, where there are insufficient resources to meet their needs. This has significant implications for the quality of life of the ageing population that is also experiencing vision problems. Clearly, this situation deserves prompt attention, in terms of social policies to sensitize all frontline personnel to the needs of the elderly, and the commitment of resources to implement community-based interventions that respect the dignity and rights of all concerned.

The status of children and youth with vision problems

In the industrialized world, over 50% of children born with vision problems have additional disabilities, and it is likely that this percentage will be significantly higher in the developing world. Of course, the prevalence of blindness is higher in developing countries for a number of reasons. First, potentially blinding conditions such as vitamin A deficiency, harmful traditional eye remedies, or cerebral malaria, which have been eliminated from high-income countries, are common there. Second, preventive measures for conditions that have been controlled elsewhere such as measles, congenital rubella, or ophthalmia neonatorum are insufficient. Third, facilities and skill personnel for managing conditions needing surgery are lacking (6, 11).

Regardless of the causation of vision loss, it is recognized that each family deals with the diagnosis of blindness or partial sight on its own. Reactions may range from acceptance of the child and his or her handicap, to denial of the effects of the handicap, or perfectionism; over-protectiveness; disguised rejection; and open rejection (13). These categories are not strictly separable but may overlap and vary in degree and intensity.

In most Middle East and African countries, for instance, it is common for the followers of the Islamic faith to view the diagnosis of blindness or any disability as "the will of Allah" (14). In these communities, some families go about their daily activities with minimal interruption, while still others undergo a long period of grief or mourning, with members of the extended family being impacted in various ways. In general, cultural or religious values can influence how a family accepts and copes with their child's diagnosis. When the family views the diagnosis in a positive way, opportunities for the child to develop a strong sense of self and experience positive interactions with others are more likely.

One common reaction among families of newly-diagnosed children is profound grief or loss as it dawns on them they do not have the "perfect" son or daughter they had expected. They become enveloped by sadness, fear, anger, and self-recrimination. Often in this type of situation, the families have had little or no contact with children or adults with a similar disability in their village or nearby community. Frequently, these parents do not understand that their child can learn, grow, and develop into a productive member of society. Their dilemmas can become exacerbated by immediate family members, neighbors, medical and school personnel, who are often not knowledgeable with the disability and its effect. In these circumstances, it is imperative for families to be directed to early intervention specialists who can provide the education and training for the child, as well as help the families understand how vision loss impacts the child's overall development, especially in the domain of social skills.

In this regard, education becomes a critical process of providing opportunities for children with vision loss to integrate into society. These children require an education adapted to their latent potential, their capacities and their needs - "special education" which will enable them to develop their skills in order to become active and productive citizens, and to attain personal development towards independence and self-image. In a sense, we view special education as a component of rehabilitation. It is needed for all those individuals who experience (or are faced with the risk of experiencing) significant and continuing difficulties in learning and adjusting to normal educational opportunities made available to other children. But such education is best provided within the milieu of the family dynamics in a manner that integrates the child within her/his naturalistic environment. In our opinion, this is what is exemplified in both quality of life and family quality of life principles in the field of intellectual and developmental disabilities, which have the potential of fostering the self-image, growth and independence in people with vision impairment throughout the world.

From our experience, statistics on special education in Africa and other developing countries are scarce. Data are not always comparable and do not cover the entire developing world. However, available statistics have been used to construct a pattern likely to apply over broad areas with similar profiles (9). In examining situations from the four continents in the developing bloc, Klingberg projected certain identifiable trends regarding the numbers and percentages of school-age children who were blind, in the 30-year period (1970-2000). Some of Klingberg's observations (9) still have far-reaching implications for policy-makers in the field of blindness. The highlights of her findings may be summarized as follows:

- The astronomical increase in Africa’s population will limit the effect of all achievements made for people who are blind due to pressure on resources.
- Of the four continents taken as a whole, the risk of becoming blind is lowest in Latin America (0.5%) and highest in Asia (1.8%).
- There are great discrepancies in service provisions for children who are visually impaired. For the Arab States and Latin America, it is about 2%, for Africa 1%, and in Asia only 0.1%.

Obviously, to promote the well-being and satisfaction of these marginalized citizens requires providing them with opportunities equal to those of the whole population and an equal share in the improvement in living conditions that will translate into social and economic advancement. One practical measure that needs to be considered is for professionals, policy-makers and frontline personnel in the developing world to adopt models of education that can respond to the cultural needs of consumers, and empower them to make informed choices within their own communities, in line with prevailing economic realities. Indeed, in all educational and rehabilitation activities, empowering consumers should be the bedrock of workers’ efforts to making their services inclusive.

The critical question here is: How can such a goal be attained in low-income countries’ services with a system of education that has largely evolved from patterns established in the West? This is an important area which deserves serious examination because, as we have often seen, services will fail unless the personalized views and choices of consumers are taken into consideration, from planning to implementation stages.

For many years, the three predominant models of special education service in most developing countries include: the residential school, the resource centre, and the itinerant programme (15,16). In the past two decades, the inclusive education system for special needs learners has been gaining popularity, as a result of the framework for action on special needs education (17). However, many challenges still remain in its effective implementation due to, amongst other factors, poor policy framework, insufficient funds to train professionals and procure equipment, low morale amongst general and special education teachers, and the absence of sound, rigorous research to ascertain its broad impacts on the system of education (18).

Issues affecting adults who are blind or have partial sight

We now examine past and contemporary practices in the rehabilitation of adults who are blind or have partial sight, and how society has dealt with their quality of life, their well-being and satisfaction. In broad terms, the major world religions have influenced, either positively or negatively, peoples’ attitudes towards persons with disabilities. For instance, both Christianity and Islam, to some varying degrees, established the practices of caring for the blind and other disability groups within the society. Obermann (19) noted that it was the emergence of Islam in the seventh century with its strong ties to North Africa that provided the new ideological perspective with regard to treatment and care of people with disabilities. The Muslims had, at that time, built a hospital in Baghdad that offered treatment in line with the best scientific knowledge of the day.

Furthermore, it was reported that a hospital had been founded in Cairo where free treatment was given to all sorts of disorders. When the patients were discharged, they were given a sum of money so they could manage until they were re-employed, thus emphasizing the dignity of work for all in the society. Such examples are probably significant developments in the practice of rehabilitation, because they provided the catalysts for present-day practices in rehabilitation.

In fact, according to Kirtley (20), the socially-oriented ideas of the time made Egypt one of the first countries to produce self-supporting scholars who were blind. Many of these scholars became revered for their ability to recite the Quran from memory – a trend that is still noticeable in some African, Middle Eastern and Asian countries, including Pakistan.

Writing in regard to Pakistan, Yasmin, Minto and Khan (21) reported that children with visual impairment have historically been educated alongside sighted pupils in the religious schools known as madrassas, where they received instruction in theology and the memorization of the Holy Quran, and later often became employed as Imams in mosques. This type of public education for the visually impaired in the predominantly Islamic country is indicative of the early recognition by the authorities to integrate capable citizens with blindness into the Pakistani society.

Within traditional African communities, in pre-colonial times, the kinship system had created in itself a mechanism for rehabilitating people with disabilities, including the blind, the aged and the poor. The process was facilitated by the humane composition of traditional communities, which were characterized by families and other types of kin groups (22). Such groups were seen to overlap in membership with other groups, and tended to be focused on the same few problems for the maintenance of the total society. They usually made similar contributions to the society as an ongoing concern.

In addition, in practice within the kinship system, social risks were covered by natural means, as dictated by customs. The contingency of unemployment in the general sense of the term (which could lead to abject poverty) was unheard of. It was usually a question of under-employment, which often resulted from fluctuations in the climatic conditions. During periods of declining activity, the food stuffs which were preserved during favorable seasons, and augmented by the products of secondary efforts, sustained the members through austere periods. In such circumstances, those with disabilities were aided by members of the kinship system.

In certain communities in Africa, informal services for persons who were blind had been incorporated into the traditional system of living. These services dealt with the simple nature of traditional society, focusing on imparting work ethics and skills that involved such occupations as: basketry, chair-caning, mat-making and weaving. There were also priests who had vision loss, as well as fortune tellers, and musicians, who emerged in other countries in Africa. In Ethiopian society, education and placement of people who were blind was vested in the Ethiopian Orthodox Church (23). Boys who were blind were brought to the church where they received instruction in church liturgy, and were required to memorize verses, books, songs, and poetry.

The forces of urbanization and the dependency pattern of development, coupled with missionary activities in most parts of Africa, over a prolonged period of time, made incursions into the kinship system, thereby eroding its fundamental structure and functions. These forces of societal change set in motion the gradual collapse of traditional learning sequences for children who hitherto, had lived, learned and interacted within the community planned group experiences. In a way then, the formal or full-time systematic instruction introduced by the missionaries and colonial administrators largely succeeded in detaching these youngsters from the realities of their everyday life. It is not surprising, therefore, that post-independent Africa is still grappling with the repercussions of Western social experimentation, which has created unprecedented rural-urban migration, diseases, malnutrition, and impoverishment of the society. Consequently, national initiatives in the past 50 years seem to aim at high cost projects which serve relatively few children and ignore the majority of children and their families who are at risk or affected by impairments.

The power and impact of creativity and the blind

Rehabilitation practitioners, educators, parents, not to mention the general public, have placed considerable focus on the unique needs of people who are sight impaired, but a clear distinction must be made between the practical daily requirements of life, and the factor(s) which bind us as evolving human beings. One definition of the quality of life model as defined by Goode (24), points in a positive direction, “Quality of life is experienced when a person’s basic needs are met and when he or she has the opportunity to pursue and achieve goals in major life settings” (p148). The question begs, what does it mean to be human and how does a variable such as blindness impact the discussion; or does it? Does the soul, assuming we can make this generalization, of a person who is sight impaired, know it? Metaphorically, does the soul of a sighted person, who is unaware, know it? A common vernacular regarding someone who does not possess understanding is “he is blind to the truth.” Figuratively speaking we know what this statement implies. The unfortunate connection between the words “blind” and “lack of understanding” is evidence of the resistance to the idea that we are one in the same humanity, pointing to the phenomenon of ableism.

Paradoxically, we are all unique, yet it can also be said that we all want the same things of life. Quality of life research in intellectual and developmental disabilities (IDD) has endeavoured to respond to this human mystery, by holding some dramatic tension between our unique humanity and common desires. On the one hand, as stated by Bach and Rioux, (25) “Quality of life is the social well-being enjoyed by people, communities and their society.” Both of the definitions thus far hint toward a hierarchy as described by Maslow, in his Hierarchy of Needs model (26). Maslow states that once basic human needs are met, we can move on toward achieving self-actualization. None of the references to a quality of life exclude, or for that matter, include eyesight. What is implied is a matter of choice, coupled with social connection. Quality of life “is both objective and subjective, involving material well-being, health, productivity, intimacy, safety, community and emotional well-being” (27). Here, we are reminded that blind people are just as heterogeneous as the rest of society’s members, and we do want meaningful experiences in life as personally defined.

There are times when people are surprised to learn I (RB) am a visual artist and for many years operated a theatre company, which I founded. “How is this possible?” is a question I often receive. Words alone often fail, but the power of the imagination speaks volumes. “Imagination is more important than knowledge. Knowledge is limited; imagination encircles the world” (Albert Einstein).

The dramatic arts not only promote the workings of the imagination, but theatre featuring artists with disabilities successfully influences the public together with relevant stake holders within disability culture. This illustrates another view of quality of life as a sensitizing concept (28). I often remind my students and actors of the power of spontaneity which appears to be associated with right brain functions. Over and over I need to reinforce this idea, because for the most part, students do not believe in the power of their own creativity. We have conditioned our young people to wait for teachers to tell them what and how to think. Perhaps this is becoming a past reality, but I fear this is not the case. Blind people, like students of school or life, are often seeking approval and direction as well, and the solution remains; be creative, take a risk and go with that spontaneous idea, before the inner critic takes hold (29).

The definition of drama literally is ‘a thing done’: “Just do it and take along your imagination”. Regular participation in creative activities stimulates the imagination in general. The drama experience is no exception, plus it includes the added benefit of group collaboration, and the vital contribution of the audience. One of the actors from the Inside Out Theatre Company declared of his acting experience, "It makes me feel powerful!"(30). Isn't that what we all want from life? Isn't increasing self-fulfillment and self-actualization throughout the lifespan, beyond basic needs, what we strive and long for?

"Being. How individuals feel and see themselves. Belonging. Part of a family, community, employment. Becoming. What they think they want to be or achieve" (31). This view of quality of life is in dynamic relationship with the power of the dramatic arts for people who are sight impaired. The drama workshop or rehearsal is rich with process and potential for becoming. Roles can be played, tried on, and practised with others in practical ways, which transcend the spoken word alone, and foster a holistic approach to learning. Many of the actors from "Inside Out Theatre" go on to secure employment in the community as a direct result of skills practised in drama classes, where feedback is received in a safe and enjoyable environment. Here the enjoyment factor must not be underestimated, as research continues to support the benefits of laughter for the wellbeing of all (32). The dramatic process is also social by nature, giving an opportunity to test out interpersonal skills, and even develop healthy friendships. A quantitative studied carried out with blind adolescents showed the decided improvement of social skills after a four day drama workshop (33).

Eye contact, so important from a sighted social perspective, can also be practised within a dramatic arts context, due to its highly social nature. Very few legally blind people are actually totally without some residual vision, a fact which is confusing to people who can see. The legal definition of blindness specifies a visual acuity of 20/200 in the best eye after all possible correction, or a visual field of less than 20% in diameter (34). In other words, not only are blind people unique from one another by choice, but there also exists distinctions regarding levels of visual acuity. Some may have little challenge with maintaining eye contact, but might benefit from movement activities in rehearsal or on stage. Movement, together with the development of body awareness, promotes the ability to navigate real world environments with ease and safety. Blind people are constantly being watched by the curious public; becoming comfortable with acting in front of an audience develops skills that transfer from the stage to life.

A segregated drama experience for people who are blind or partially sighted, can offer tremendous emotional benefit. A healthy sense of belonging cannot be overestimated. As a legally blind student in primary and secondary school, I (RB) participated in a totally mainstream education experience. Academically and socially, I kept up with my sighted peers with little difficulty. Nonetheless, I experienced feelings of isolation and alienation, especially as high school graduation loomed. To my relief, I was referred to a segregated summer camp for legally blind teens, which fed a part of my 'soul' that no other experience could have accomplished in my otherwise totally mainstream lifestyle. For this reason, when I became the Family and Children's Counsellor for the Canadian National Institute for the Blind, Southern Alberta, I vowed to provide similar opportunities for the educationally integrated children and teens on my caseload. I can still recall the expressions of relief from the youngsters, who could, for a precious hour or two, compete with others on equal ground. My programs often included drama activities, which were enjoyable, and offered opportunities for rich and personal discussions about being different.

The power of the imagination is undeniable. In fact, a trained master hypnotherapist knows that the subconscious mind actually does not know the difference between what we refer to as reality, and fantasy. All we need do is exercise the imagination. There are myriad ways of accomplishing this, but in my experience the dramatic arts hold one of the best and most enjoyable possibilities. Wassley Kandinsky (35) reminds us that art is an expression of the soul. Notice that he does not suggest that art is an expression of the sense of sight? In fact, according to artist, Lisa Lipsett (36), true creativity transcends the entire left hemisphere of the brain. Lipsett's academic research indicates true creativity comes with using the non-dominant hand and eyes closed while painting.

Neuro-science is making interesting discoveries regarding the plasticity of the human brain. Blind and sighted subjects are proving to reveal some profound findings. Shimojo and his colleagues, through quantitative research, have shown that sound can create images, otherwise referred to as visualization, "Our findings indicate that visual perception can be manipulated by other sensory modalities" (37).

Further research by Harvard neuro-scientists, using blind subjects, has made major contributions to our understanding of the brain's ability to adapt and create. Studies in neuroscience show major interactions between different sensory areas of the brain. In other words there seems, at the level of the central nervous system, to be associations between senses which provide holistic and different ways of perceiving. This suggests holistic mechanisms which involve a multitude of sensation which, for example cannot be viewed as purely visual or auditory "The world of the blind can be especially rich in such in-between states—the intersensory, the metamodal" (34). Long past are the days when the contributions to society from the rehabilitation of the blind are limited to talking elevators and voice activated communication devices. Science wants our brains!

Theatre artists and creative thinkers in general, have always known the power of the imagination, but now science seems to be catching up. The difficulty, of course, is science is still not able to quantify the imagination, but there are hints which point toward the belief, that creative people have a greater chance of developing sensory crossovers, sometimes referred to as synaesthesia. Oliver Sacks, in his ongoing research on blindness refers to a woman, called Tenberken, with impaired vision from early in life who associated words and numbers with colour. Later in life she could only identify form and objects by using colour which must have required some form of synaesthesia. She described herself as a creative person, who was always interested in paintings and colour.

My own experience with colour perception, although not completely understood, did begin during a time in my life when I was taking on the Inside Out Theatre Company fulltime. At this point in time, we are certainly not able to confirm a direct link between perceiving colour in the environment by the blind and participating in drama, but we do know something about light, and colour; to sighted people as "we who live in the world of reflected light…". I like that. It is not as though the sighted have something the blind do not; we just live in different light worlds! All colours exist around us at all times, and are absorbed by our physical surroundings, save for what is reflected. On a purely physical plane, I have not been able to perceive colour for many years. Yet, I am able to perceive beautiful and vibrantly alive colour in my environment at virtually all times. Is it not plausible that I am simply seeing what is there, (what is normally being absorbed) and thus a part of my brain has developed this ability?

Oliver Sacks (38) has written extensively about a phenomenon called, 'Charles Bonnet syndrome,' which suggests that what I perceive is a hallucination. I feel it is important to remember that hallucinations cannot be managed or controlled. In my case, this is not entirely true. Furthermore, from a quantum physics perspective the colours can be explained, so perhaps neuro-science is not always the research route to consider. Furthermore, since the year 2009, I have begun painting and my works are alive with colour. Since this time, my awareness of perceived colour in my surroundings has increased in intensity and meaning, and I am not alone. In a YouTube video, Carol B. Saylor (39), who is an artist, shares a similar phenomenon. She speaks of this in an exhibition called "lumination". In this instance, the artist happens to be blind, but countless testimonials exist from people who see colours while engaging in musical activities of all kinds, not to mention people who have meditated for extended periods of time. They too report colour perception with eyes closed. Also, many musicians such as Paul Armitage share reports of seeing colour while playing, or even learning to master the piano with the aid of colour perception not unlike what I experience.

At this juncture we are reminded of Jacques Lusseyran's observations about what I refer to as the 'often deceptive yet seductive' quality of physical sight. Lusseyran asks, "Aren't we seeking a way to base teaching entirely on visual impressions?", and goes on to say, "Yet it is not the process of seeing that I attack. I accuse only a certain idol worship. The idol is the conviction that seeing is the principal activity of the spirit, and sufficient for it" (40). Practically speaking, I dream of a day when I can drive a car, do my own shopping and spontaneously take a solo walk with ease and confidence. But, then I wonder, would I become distracted and overwhelmed by the bombardment of visual stimulation in my environment; would I lose my colours; my peace of mind? It would seem to me, that many sighted people have engaged in years of disciplined meditation to obtain what I have developed naturally.

Here we are dipping deeper into the workings of the imagination. “Imagination dissolves and transforms, unifies and creates, while drawing upon the ‘lower’ powers of memory and association. It is by such imagination, such ‘vision’, that we create or construct our individual worlds” (40).

Central to this discussion is, of course, the experience of the blind performer. In this regard, I would like to give the final word to Kelly MacDonald, Artistic Director of Out of Sight Productions, a theatre company in London, Ontario that features blind actors: “For a blind person being introduced to acting, setting your foot on stage for the first time gives a sense of empowerment: Like suddenly being able to fly an airplane. Something you might have never thought you could actually do and now you are doing it. Getting a chance to take the dream and make it reality” (personal e-mail correspondence with author).

Socioeconomic impacts of vision loss on families

So far, we have discussed people with visual impairment and the contexts in which they live; the other context which is critical is the family. Families play a major role in helping to promote the overall development of a child, and the value systems of the parents (and the wider family) are powerful determinants of how a child with vision problems will adjust in society. Therefore, family members are indisputably the most significant advocates a child can have. In affluent countries, families are now assuming increasingly important roles in advocating for resources and services for their children with special needs. Their efforts have yielded substantial outcomes that have resulted in quality education, community living arrangement, and employment opportunities. Parents also face challenges, and many of these aspects discussed in Zuna, Brown and Brown (41) have application in this context as well. For example, some of these parents have demanded, and are receiving, respite care, to allow them a measure of satisfaction and well-being. Such ancillary services have proven valuable for their children who have been trained to be self-reliant members of society.

The second author of this chapter (RB) represents a remarkable example of an individual who grew up and attended mainstreamed schools in Canada. Subsequently, she founded a theatre company known for its consciousness raising powers worldwide. Through her creative abilities, she tells stories designed to enlighten her diverse audiences about human services and the potentials of people who are blind. In her activities (on and off stage), she is often guided by the reality that risk-taking enhances one’s creativity and career advancement, and she acknowledges that it is this philosophy that has taken her performances on the stage to higher levels in recent years. It is suggested that frontline personnel in human services embrace this risk-taking paradigm as a practical way of promoting self-determination and empowerment of their consumers.

In most developing countries, advocacy organizations are still in their infancy, and governments have been slow in focusing effectively on modern care and treatment of persons with disabilities in general. Compounding the situation is the reality that there are no social safety nets or respite care available in these countries (14). Yet, most households continue to function under mounting economic and social pressures, and general insecurity within the community. The high rates of poverty and illiteracy in the population also imply that these families lack the knowledge and power to make critical decisions that will entitle their children to quality education and appropriate community living experiences.

Thus, in a depressed social and economic climate, individuals with vision impairment and their immediate family members have to cope with substantial debilitating consequences. Needless to say, vision loss imposes restrictions on the ability to move about and control self and environment, particularly in low-income countries, where a high proportion (75%) of those with sight difficulties require assistance with daily tasks, and where misconceptions about blindness still predominate in the wider society. Such negative attitudes may be disempowering for the non-risk-takers with vision loss. As an illustration, the first author (PMA) could recall instances in previous years when he undertook independent travel in urban areas in Nigeria only to be confronted by overzealous sighted individuals who approached him and moaned his not having a sighted child or adult to accompany him everywhere because of the perceived danger in the society. Similarly, a single lady who is blind in another African country once narrated how a concerned young man ran towards her on a busy street to talk about her vulnerability to sexual assault if she continued to travel independently with a cane, rather than with a sighted guide. The young man acknowledged that the beauty of this blind woman could “invite” unnecessary attention from boys or men who could harm her, even in broad daylight. The fear that enveloped the lady eventually forced her to hire a sighted guide, which led to greater financial costs and loss of autonomy.

Unfortunately, in a number of developing countries, specialized transportation and in-home services are absent. Most adults who are blind (especially girls and women) often resort to being led by sighted children, based on their perceived insecurity or lack of self-defense skills. However, the reality is that when a child assumes the role of a guide or caretaker, that child is often prevented from going to school, or enjoying a lifestyle similar to that of her or his peers. Such a practice results in denying the child the opportunity to acquire a quality education and escape the cycle of poverty. By the same token, when a sighted adult becomes the caregiver, then employment is interrupted. Clearly, there are long-term repercussions for economics, education, and human rights that extend beyond the individual who has the vision loss, implying that the social fabric of the family and the community is impacted on a practical level.

In high-income countries, the quality of life model is increasingly being applied to the framework of policy and management planning in intellectual and developmental disabilities. The practice has created transparency in service delivery and enhanced understanding of needs and wants of consumers. Schalock and Verdugo (42) argued that in order to promote the self-actualization of consumers, and to enhance decision-making by agencies and the society, it is imperative to use evidence-based practices to identify and sustain the individual’s needs, supports, interventions, diagnoses and assessments. This framework will ultimately lead to organizational structure that reflects individualized needs and positive public outcomes. In the context of low-income countries, we suggest that government and private agencies adopt the bottom-up approach implicit in the quality of life model as enunciated by Schalock and Verdugo to meet the needs of people with vision impairment, their nuclear and extended families, and the wider community.

Recommendations for future direction

To successfully tackle the problems already identified requires concerted efforts and practical interventions at all levels, especially in developing countries. Assisting people with sight loss in these countries appears more complex when compared to the developed world. Furthermore, prospects for tackling the problems effectively are getting worse (43), given the findings that Africa, Asia, and Latin America have the greatest number of “weak” countries in terms of economic and social criteria. These world regions are severely challenged not only by formidable social and economic constraints, but they also have the largest percentage of persons who are blind or partially sighted, and most of these nations are heavily dependent on foreign aid, or at best on borrowing. This situation further limits the capacity of most governments to formulate practical and meaningful social policies. The suggestions made below should be examined critically, with a view to resolving most, if not all, of the problems impeding the development of quality of life for this segment of the population.

A. Establishing a vision impairment database in each country

Similar to that of the World Health Organization (44), the vision impairment database will be responsible for the collection, storage, retrieval and dissemination of data on vision impairment, with emphasis on avoiding blindness and partial sight. Such a measure is desirable, since a considerable proportion of vision problem is preventable, or relatively easily curable (5,10,45). There is no doubt that, at the moment, numerous countries still lack reliable information on the number and distribution of persons who have vision loss.

B. Increasing access to medical care

Programme planning needs to be linked to eye care services. However, eye care specialists (ophthalmologists, optometrists, opticians, etc.) are in short supply throughout the developing world. The training of these specialists is critical to meeting the needs of the population, and to intensify the research into the causes of vision impairment, together with the study of the cultural and psychological implications of vision loss. More importantly, the training of these professionals should emphasize, among other things, the personalized needs of children, youth and adults who are totally blind or have low vision.

C. Initiating public awareness campaigns in each country

The education and rehabilitation of people with vision difficulties should not be seen as an exclusive concern of one government agency, but that of every single citizen with a tinge of human empathy for the less privileged members of society. A campaign of this nature, involving each country's ministries of education, social development, health, and information, could be embarked upon to awaken public consciousness of this class of citizens, their needs, aspirations, and potential prospects, and to mobilize public consciousness and efforts towards the noble role of being a brother’s or sister's keeper.

D. Establishing a sound funding base for special education and rehabilitation programmes

Funding is a crucial factor in the development of specialized programmes and services for persons with vision impairment worldwide, and the funding problem is more critical in low-income countries. It is stressed that the less affluent countries initiate a plan for funding development to support essential social and rehabilitation services. Periodic fund-raising activities can be undertaken in conjunction with private national and international organizations and philanthropic individuals. Monies realized in this way should be promptly allocated for specific services at a given time.

E. Setting up industries for the manufacture of special equipment and materials

With the economies of most developing countries under serious strain, one good and useful lesson is that of looking inwards. Since foreign exchange is hard to come by, those involved in working with people who are visually impaired must tailor their services in such a way that they will not rely on costly, or often imported, raw materials, equipment, and technology. Indigenous entrepreneurs could be engaged in the design and manufacture of miscellaneous instructional and rehabilitation devices, e.g., mobility canes, writing slates and styluses, and mathematical devices. Also, talking book machines and recordings could be locally developed to provide an alternative medium of literature access to people with vision loss.

F. Expanding the scope and functions of the employment bureau in each country

The way and manner in which an individual earns a living does much to determine his/her status in the community and the individual’s perception of self-worth. Remunerative work provides the earnings needed for shelter, comforts, and luxuries. In fact, employment gives the individual a host of other benefits, including: a way of life, a source of expression for his/her personality, a level of social status, a constructive way of using time, and a yardstick for measuring the person’s progress and growth. The educational system has an obligation to inculcate these skills in every individual. This demonstrates the need for expanding the roles of the employment bureau in each country, whose principal goal would be to serve as a liaison between training agencies and potential employers. The employment bureau should be given legal backing by the government, so it can prohibit discrimination in the employment of qualified and competent persons with disability.

G. Raising the self-image of people with vision loss

In the developed countries, attention has been given to raising the self-image of people with disabilities through advocacy and professional groups. Individuals with visual and other disabilities are frequently involved in educating the general public regarding their potential. In some cases, people with disabilities are involved in teaching their counterparts various skills which are highly appreciated by peer groups. It is recommended that such a strategy be adopted by policy-makers and practitioners in the vision impairment field in developing countries.

H. Supporting frontline personnel to participate in in-service training programmes

The lead author (PMA), who has conducted numerous workshops in Nigeria and elsewhere, has observed the limited participation of rehabilitation and social workers, and special educators in workshops and training programmes which would broaden their knowledge and enhance their practical intervention skills needed to deal with consumers and their families. These frontline staff are often excluded from international training workshops in favour of their countries' elites or bureaucrats. If meaningful advances are to be made in terms of instilling in workers practical knowledge and skills, international agencies that organize programme and staff development must ensure that opportunities for participation are extended to these frontline personnel (who play a major role in service provision in each country) due to their familiarity with indigenous customs and mores.

More fundamentally, any type of training must be clearly linked to consumers' personal views, needs and wants - values which frontline workers already appreciate. It is recommended that all newly designed training curricula for persons with disabilities (and community workers) must emphasize, among other things, such topics as: inclusive education, community-based rehabilitation, self-image, personal values, human sexuality, career counseling, job placement, and orientation and mobility requirements.

I. Encouraging creative and artistic expressions in individuals who have visual impairment

For many centuries, and throughout the world, persons with blindness and other disabilities have demonstrated their extraordinary abilities and talents in creative art, music, drama, and poetry. Such individuals have emerged within developed and developing societies, where they made substantial contributions to their own quality of life, as well as the well-being of their extended family members. Ruth Bieber, the co-author of this paper, illustrates a clear example of a professional arts consultant with vision difficulty who has carved a niche for herself in the theatre arena (46). Throughout the world, she has led her group to entertain and educate audiences about developing positive attitudes towards people with difference, and the need to foster their acceptance within the society. Her testimonies attest to what can be achieved if persons with disabilities are encouraged to flourish within their boundaries, in a manner that will advance their quality of life.

Conclusion

In summary, policy-makers and practitioners in low-income countries must learn from lessons that have emerged from studies of individual and family quality of life in the industrialized world. The stakeholders need to carefully examine available data and practices that might enhance the outlook of persons with vision problems in each country.

In this regard, it is imperative to recognize frontline workers in particular as significant change agents in the promotion of the well-being of consumers and their families, consistent with their cultural beliefs and dispositions. Finally, to ameliorate the challenges in human service provision that have been identified in this paper, policy-makers must understand that vision impairment is not an issue that confronts any one nation alone. It is a global phenomenon, the solution of which calls for international research efforts and collaboration.

Throughout this paper, we have discussed the following key points:

- Empowerment of persons with vision loss over their quality of life is an important factor for actualizing their personal life goals.
- Frontline personnel should aim to develop positive self-image in persons with vision loss, and provide environments that will empower such consumers.
- Inclusion is perhaps the most widely discussed practice in regard to people with disabilities. Our view is that for effective inclusion to occur within schools and work settings in low-income countries, the right kinds of supports and resources must be available to the individual, the family, as well as frontline personnel.
- Professional values are absolutely critical to the success of both consumers and parents or caregivers. These values must reflect the desire to assist the reluctant parent to come to terms with the child's vision loss or disability. Further, the professional value system must address the child with disability within the holistic framework of service. Professionals, including educators, social workers, and health care workers, should have an objective value system that is capable of responding to the variable needs of service recipients.

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Health-related quality of life

Margaret R Kyrkou, OAM, PhD, MBBS, FRACGP, DCCH[*]
Disability and Community Inclusion, School of Medicine, Flinders University, Bedford Park, South Australia, Australia

Abstract

Quality of life (QOL) is an overarching goal individuals and families aspire to. Health represents a critical aspect of QOL, and without good health amongst all individuals in a family, life can become problematic. Consequently Health Related Quality of Life (HRQOL), and Family Quality of Life (FQOL) are important contributors to a person's overall QOL. This paper illustrates innovative methods parents and caregivers have devised to enhance HRQOL in people with intellectual and developmental disabilities (IDD), and to improve FQOL. It also encompasses strategies developed by the author, both as a medical practitioner working with people with disability and their families, and as the mother of a female with multiple disabilities including autism, IDD, and severe epilepsy. The author selected conditions which have major impact on the person with IDD, family and caregivers, using vignettes to graphically illustrate aspects of HRQOL. Some comments are not yet found in publications, as they relate to personal experiences or observations as well as personal information from parents and caregivers.

Keywords: Quality of life, health

Introduction

Until the early 1970s health researchers mainly considered the health of populations and research samples in terms of mortality and morbidity (1). However, since then self-perceived health has been recognized as one of the most important predictors of short-term and long-term survival independent of physical health measures, and is considered to be the best predictor of the use of health care services (2-4). This is equally applicable to people with IDD, but it may be the perceptions of observant parents if the person is unable to communicate effectively. As indicated by Cummins, Gullone and Lau (5) there is the potential risk that proxy interpretations of what a parent chooses could be different to those the person with IDD might choose, yet in the author's opinion, if

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[*] ***Correspondence:*** Margaret Kyrkou, OAM, PhD, MBBS, FRACGP, DCCH, Disability and Community Inclusion, School of Medicine, Flinders University, GPOBox 2100, Adelaide, South Australia 5001, Australia. E-mail: margaret.kyrkou@flinders.edu.au

the person has no obvious means of communicating choice, parents and professionals need to consider what is in the best interests of the person with IDD.

The 2001 International Classification of Functioning, Disability and Health (ICF) (6) way of conceptualising health, function and disability represented a significant shift from the previous paradigm, which presumed disability had to be associated with poor health. The ICF reflected the fact that a person can be both disabled and healthy, with a dynamic interaction between biology and context, and introduced the concept that personal participation is an important component of health. This can be illustrated by comparing two adults, both with equally impaired mobility, but one who is cognitively intact, the other has IDD.

The cognitively intact person may be financially better off, able to drive a modified car, or purchase and use a motorised scooter to access locations independently. The person with IDD on the other hand is unlikely to be able to drive or manage a motorised scooter in public, even if funding could be made available. He or she may also not be able to manage an electric wheelchair, consequently has to rely on being pushed around in a manual wheelchair, with the resultant limitation of social opportunities and independence. Although both have the same level of physical disability, the cognitively intact person will most likely have better HRQOL because of more opportunities for personal participation.

The conceptual distinction between disability and chronic conditions is complex and interrelated (7), but at the same time disability can be both a risk factor for chronic health conditions as well as being an outcome of living with those chronic conditions. This raises the question of how well can functional abilities such as inability to walk serve as indicators of health status if they have been present all the life of the person with IDD, and have been stable for many years.

Quality of life

As described by Brown and Faragher (8), there are many definitions of QOL relating to people in the general population, but in the field of IDD it is commonly accepted to relate to wellbeing (social, emotional and material), as well as health, intimacy, safety, productivity, and community aspects. A person with IDD is considered to experience QOL when basic needs are met, and the person has opportunities to pursue and achieve goals in major life settings.

Two aspects of QOL of particular importance to people with IDD are FQOL, which is reported in detail by Zuna, Brown and Brown (9) and HRQOL, the subject of this paper. A person could not be claimed to have good QOL if either of those aspects are deficient.

Health-related quality of life

It was not difficult to find articles with HRQOL in the title, but many authors used the term without offering a definition. None of the references located had any mention of disability in terms of IDD. If the term ‘disability’ was used at all it was in the context of a disabling physical condition in a person without the associated limitation of IDD. A cognitively intact person who has a disabling physical condition has the potential to be able to understand the issues, and compensate for them by being able to buy and use appropriate equipment, unlike the person with IDD.

Efficace et al. (10) declared that despite a number of studies incorporating HRQOL, at the present time there is no single definition of HRQOL, although there is broad consensus that it refers to the physical, psychological, and social functioning of patients, and the impact of disease and treatment on their abilities and daily functioning. The Centres for Disease Control and Prevention (11) divided HRQOL into two levels. First the individual level, which includes both physical and mental health perceptions and their correlates, encompassing health risks and conditions, functional status, social support, and socioeconomic status. Secondly the community level which includes resources, conditions, policies and practices that influence a population’s health perceptions and functional status.

Measurement of HRQOL

The ‘gold standard’ of generic HRQOL measures is the Medical Outcomes Study Short Form-36 (SF-36), (7) initially developed in the 1970s but with recent updates (12). It has scores on eight domains: Physical Functioning, Role-Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role-Emotional, Mental Health, plus two summary scores of Physical Health and Mental Health.

The difficulty with the SF-36 in relation to people with IDD is that the physical domain has questions regarding walking, climbing, kneeling, and lifting without differentiating long term physical impairment versus recent deterioration. In medical practice, the author sees many people with IDD who have problems climbing or kneeling due to poor balance, and lack of body awareness, but are medically healthy. However, because of the inclusion of three physical domains (Physical Function, Role-Physical, and a summary score of Physical Health) the person's score on the SF36 falls inappropriately into the poor health range.

Rationale for writing this paper

The information in this article is collated from a number of sources, including self-report, parental and caregiver responses to a postal questionnaire for the author's PhD thesis (13), and the author's personal experiences as the mother of a daughter with IDD. As Medical Consultant in a health unit supporting students with IDD and high health needs, mostly involving invasive procedures, the author has seen first-hand the impact on FQOL when agencies fail to provide services promised to the family.

Working in a medical developmental disability unit as a general practitioner, the author has been concerned to find teenagers and young adults with IDD referred for a psychiatric assessment for challenging behaviour often subsequently found to be due to unrecognised pain, medication side effects, or anxiety. Treatment of those underlying conditions resulted in resolution of some if not all the symptoms.

The importance of increasing understanding and knowledge of the health needs of people with IDD in professional and everyday life is discussed. Vignettes are included to enhance the value of this chapter for people with IDD, their families, and service providers including treating clinicians, as QOL is largely defined qualitatively rather than quantitatively. Vignettes provide a powerful means of assisting the reader to 'walk in the shoes' of not only people with IDD, but all those impacted by their circumstances. The impact can be likened to the ripple effect of a stone thrown into a pond – the 'ripple' effect may start with the person with IDD, but from there it radiates out to family and friends, caregivers including clinicians, and in many instances to wider communities such as schools, post-school services, leisure activities, accommodation services, and the local neighbourhood.

As Brown and Faragher indicated (8), there are concerns that the validity of the cognitive ability of people with disability to self-report reliably has not been examined adequately (14), and that such research is necessary to better inform efforts to measure self-assessed HRQOL by persons with cognitive impairments. Although researchers try to compensate for the cognitive impairment, the fundamental problem of functional bias still persists, and new measures of self-reported health are required to be able to determine the relationship between health, function and disability.

Although many individuals with IDD may not be able to completely self-manage in all situations without at least some support, there are many innovative practices which can assist the person to progress along the pathway towards health-related self-management.

Communication and QOL

It could be argued that assisting a person with IDD to communicate is the underpinning basis of QOL, enhancing self-image, self-esteem, and social-emotional development. Additionally, it may then assist the person to indicate symptoms of health problems, allowing for earlier diagnosis and treatment.

The tendency to equate communication with talking is unfortunate, as it not only involves spoken speech, but also understanding, and the ability to communicate without speaking, known as non-verbal communication. In the same way as a traveller learning another language in addition to his or her mother tongue is able to understand more than he or she is able to speak, it is easy to underestimate how much the person with IDD understands without closely observing the person's reactions and attempts to communicate over time.

Assisting the person with IDD to communicate

- Ascertain the communication ability of the person with DD instead of assuming inability to communicate.
- If the person is not able to communicate very well, give eye contact, and speak to him or her at times.
- Ask simple questions requiring yes or no answers acknowledging that the person with IDD is the prime person.
- Some people with IDD have echolalia, repeating the last word or phrase of a sentence. If a clinician frames a question with the correct answer last, when the person gives the correct answer, he or she may have understood and answered correctly, or the person may have been just repeating what was heard last.
- People with IDD may answer 'yes' to every question (14), wanting to please, imitating others without understanding that an answer could be Yes or No depending on the question. Some have different intonations of 'No' to indicate yes or no, which parents or caregivers may be able to interpret given the opportunity. A person with IDD saying yes in response to a question cannot be considered to have given informed consent if the level of expressive and receptive language has not first been ascertained.
- If the person with IDD does not appear to understand, a common mistake is to talk more loudly, which may frighten and intimidate the person (15).
- If the question is rephrased, the person may have been working out what the questioner was asking, but if the wording of the question changes, he or she has to start all over again trying to decipher the question.
- Another common mistake is to use a sentence too long for the developmental age of the person, not having considered what developmental level he or she has reached.
- Unless the person with IDD has marked visual impairment or gaze impairment, eye movements and facial changes are important non-verbal communicators. The person may not gaze fixedly at what he or she wants, just a brief look at the desired object or choice, which if missed, may not be repeated, therefore the person is considered not to be able to communicate. The person may also gesture in an indeterminate manner, but in the author's experience the eye gaze is more often accurate. The intention of the person to grab something in the consulting room may be obvious from watching for eye movements before any body movements reveal the person's intention.
- Pulling another person by the hand to what the person wants, banging on the refrigerator door, or taking a bottle or cup to an adult are other ways a person with IDD indicates need such as hunger or thirst. People with more physical limitations may use augmentative communication devices (8).
- If the professional turns to speak with the carer, completely ignoring the person who is the patient or client, it does nothing to enhance the person with IDD's self-esteem.
- By focusing solely on the accompanying person, the health professional risks overlooking important non-verbal or communicative body language.

If the person with IDD is not assisted to communicate when younger by using non-verbal means such as pointing, signing, picture cards or electronic communicators in the absence of spoken language, the risk is that the he or she will become increasingly frustrated at not being able to make needs known, resulting in behavioural difficulties. Difficult to manage people with IDD are more likely to be placed with other difficult people, further limiting social and learning opportunities. The unfortunate outcome is reduced QOL for the person, and it might mean reduced ongoing family contact.

Many children with IDD are not placed in front of mirrors. A few cultures do not allow children to look in mirrors, but more commonly either the parent or caregiver has not thought to do it, or they are frightened the child will break the mirror and get hurt. Not understanding what his or her body looks like reduces the ability of children, and later, adults with IDD to indicate the site of pain.

It cannot be assumed that a person with IDD who has good expressive language skills will either say he or she has pain, or point to the site of pain. This has significant implications for health clinicians who may erroneously assume that because the person with IDD does not state the presence of pain, there is no pain. The following vignette illustrates the medical implications (13).

- Has an abnormally high pain threshold. She recently had to have an appendicectomy after she had been mildly unwell, with some fever and 'sore tummy'. Her appendix was gangrenous and ruptured, and she spent almost 3 weeks in hospital as she developed abscesses, yet usually able to state she has pain.

The impact of medical conditions on HRQOL and FQOL

Irrespective of whether or not a person has IDD, poor health has the potential to markedly reduce FQOL. The conditions discussed in this article illustrate not only the impact on the person with IDD but also on family and extended family members, friends and service providers. Epilepsy and diabetes were selected because they both unpredictably require emergency management within minutes of onset of symptoms, and tube feeding because of the constancy of regular feeds during the day, and for some, the night as well. The recognition of pain was selected because of its pervasive impact on people with IDD, as well as those around them. The impact on FQOL will vary according to the health conditions, whether the person with IDD is a child or adult, and the person's communication ability.

Whereas HRQOL refers to the state of health of individual family members and sometimes extended family, FQOL represents the summation of all these individuals, not only of health status but also physical, psychological and social functioning. One family member with sub-optimal HRQOL, for example with chronic pain, can actually impact on the QOL of the whole family as illustrated in the following vignette.

People with IDD and CP not able to weight bear require lifting onto beds, and in and out of chairs and cars. Whereas in schools and other services, the person is moved using a lifter and sling, or is a two-person lift if a lifter is not available, there is often only one parent at home when lifting is needed. If there is adequate room to use a mechanical lifter at home, parents are advised to use the lifter while the child is still young, to get them used to being lifted in a sling. Some parents continue to manually lift the child 'because it is faster' but an older child introduced to a lifter often cries or screams with fear at not feeling supported when being lifted. This upsets the parents and consequently they (often mothers without others to assist) revert to manually lifting, and end up with back injuries. Constant pain causes the parent to become tired through lack of sleep, and irritable towards family members as well as friends, not wanting to socialise. Because the pain is hard to control when still required to lift, siblings may be expected to assist, risking them also injuring their backs. When in pain, parents and siblings may resent what the child with IDD 'has done to them'.

For some families living in homes with bedrooms, bathroom and toilet not large enough to fit in a lifter, or in rental properties where modifications are not permitted, the whole family has to be uprooted to move to a more suitable house. This is more likely to be in a different neighbourhood, away from family, friends, community and familiar support services, severely impacting on FQOL.

Tube feeding

Coincidentally with the advent of integration, inclusion and normalisation (8) medical progress was such that increasingly more premature babies were being kept alive, with an increase in the number of children with cerebral palsy, breathing and swallowing problems (16). Babies with swallowing difficulties were prone to pneumonia caused by food and fluid going into the lungs (known as aspiration), and often died from recurrent pneumonia, before the availability of tube feeding.

Availability of tube feeding was a two-edged sword for parents, on one hand relieved of the daily anxiety of trying to feed the child by mouth, with frightening choking episodes, seeing much of the food or fluid being pushed out of the child's mouth by reflex tongue thrust, and worrying about lack of weight gain. On the other hand it meant a restricted availability of carers in home, educational, respite and accommodation settings, as they needed to be specifically trained to give tube feeds. It also increased hourly costs for the child's care, consequently reducing the number of hours of support available when total funding was rarely able to be increased by services.

Some babies are later able to manage oral feeding even if only pureed food and thickened fluids, but many need gastrostomy feeds and nil orally for life. This has implications for giving medication, as a trained caregiver has to be available. Some people require overnight feeding to provide adequate nutrition, disrupting parent sleep. Leaving home, all equipment has to be taken, and arrangements made to wash used equipment. The person with IDD misses out on the pleasure of tasting food, with impact on socialisation when others are sharing food, such as at birthdays.

Epilepsy and a QOL approach

Espie et al (17) lamented the paucity of studies on epilepsy and psychopathology in people with intellectual disability (ID) despite epilepsy prevalence rates being thirty times higher than in the general population. At the same time, epilepsy is the most common illness in adults with an ID (18), and is often severe, refractory, and associated with physical disease burden. There is a strong clinical suspicion that this physical morbidity is compounded by an equally severe impact on individuals' psychosocial well-being due to exclusionary practices.

Researchers found varying rates of epilepsy in people with ID depending on the population sampled. A prevalence rate of 16.1% was found in a Welsh population (19), and a prevalence of 26% in a population based study in Leicestershire, United Kingdom (20). Those with the most profound ID have the highest rates of epilepsy, and highest mortality rates from all causes, with 68% experiencing seizures in spite of taking anti-epileptic drugs.

A literature review of epilepsy in people with ID (21) highlighted the impact on the lives of individuals, affecting physical morbidity, with increased mortality and increased caregiver burden, but effective epilepsy management has the potential to impact positively on the mental health of carers. Research (22) suggests parents of children with both epilepsy and ID are at risk for increased stress, however precipitating factors have not been studied. Structured interviews by Espie et al (17), revealed one-third of patients with epilepsy & ID met criteria for possible psychiatric disorder, particularly affective/neurotic disorder, twice the comparison rates for ID alone, however behavioural problems were lower than the population norms. Around half of the family carers reported significant stress, with one-third exhibiting clinically significant anxiety symptoms. Side effects from the anti-epileptic drugs contributed to carer stress, with young carers reporting feeling more stressed (20).

Impact on FQOL of epilepsy as well as IDD

This section will focus on the more specific impact of epilepsy in addition to IDD, whereas the more generalised impact of IDD will be discussed later in this paper. Although numerous studies have related to adults with IDD, only five were discovered which involved cohorts of adults with both IDD and epilepsy (17). A person with IDD who also has epilepsy has poorer life skills, and is more likely to have problems with continence and walking (17). Of great concern to parents (20) are the many clinicians in primary care lacking the knowledge and expertise to manage people with either epilepsy or ID, let alone with both conditions.

Although there are family stressors with all chronic childhood conditions (23), behaviour problems occur more frequently among children with neurological problems than amongst children with other types of disorders (24). Austin et al(25) identified stressors for parents of children with mild IDD as well as epilepsy.

- Concern about the child including fear of dying during a seizure, cognitive effects of seizures, education, independence, child's future, self-esteem, frustration, transitions and behaviour problems.

- Communication with health care providers, including doctors ignoring what parents feared were side effects of anti-epileptic drugs, and lack of timely information provision.
- Changes in family relations, lower socio-economic status. Low family mastery, sense of control, family organization, level of co-operation, family emotion. Low parental confidence in ability to manage the child's behaviour problems was associated with increased child behaviour problems. Increased family stress with siblings not getting along, not wanting the child with epilepsy around. Maternal perceptions of the healthy sibling's adjustment rated higher if the mother was confident in her own ability to manage her child's epilepsy, in addition to a strong marriage.
- Interaction with school (this would equally apply to adults in services) including concern the child's needs were not being met, concern about the child's safety, and limited communication from the school.
- Support within the community. Dyson (23) noted that as the number of stressors increased, including work issues, financial issues, availability of family counselling, and respite care, family function (family organization, and communication) worsened. When the person with IDD has severe epilepsy, often requiring emergency hospital treatment, and there are young siblings in school, elaborate contingency plans have to be made to ensure they are collected from school and cared for until a parent is able to be with them.

In institutions, using rectal diazepam to manage prolonged seizures was standard practice, as privacy was possible. With deinstitutionalisation (8), using rectal diazepam was no longer feasible, and a newer protocol for managing prolonged seizures was adopted, using midazolam drops (INM) into the nose (26). Being faster acting, midazolam also controlled prolonged seizures more rapidly. Parents began using INM at home to control prolonged seizures, only calling an ambulance if the seizure was not resolving or they were concerned about the pattern of recovery. Although the protocol was first developed to benefit people with IDD, as its effectiveness was recognised, it was prescribed for anyone with a history of having had a prolonged seizure and at risk of further prolonged seizures. The following vignette illustrates the improved FQOL when using INM for the person with epilepsy and IDD.

A single mother of five daughters (separated from her husband), said when rectal diazepam did not work fast enough, she had to call an ambulance to go to hospital. If in the middle of the night, she had to get her other four daughters out of bed and into the car to follow the ambulance. Once in emergency, and her daughter often admitted to hospital, she had all five girls to keep an eye on. Even if discharged from emergency, they were rarely home in time for the girls to go to school, so they missed some or all of the day. If the daughter with epilepsy was admitted, the mother had to try to get her mother to collect the girls from the hospital and look after them until she was back home. Once prescribed INM, if her daughter had a seizure during the night, her mother would give her the INM, which was generally effective, and after a while she and her mother could safely sleep. The four sisters slept peacefully though the night, ready for school the next day. FQOL improved for all six of them, and the girl with epilepsy could stay in her own familiar environment in spite of having a seizure.

Diabetes mellitus

Diabetes mellitus, due to lack of insulin, occurs in two forms, Type 1, and Type II. The World Diabetes Foundation (27) reported an estimated prevalence of 6% in adults in the general population, whereas research involving people with IDD found prevalence rates of 4.3% (28) and 11% (29). People with Prader Willi syndrome had an even higher prevalence rate of 25% (30). People with Type I diabetes require frequent finger prick blood glucose testing and insulin injections. If the blood glucose level is too low the person requires careful emergency management to restore the blood level before it has adverse effects on the body. It is also a problem if the blood glucose level goes too high.

There is no reliable estimate (15,27) of the prevalence of diabetes Type II in people with IDD, although in a postal survey of people with ID and diabetes mellitus in one region of the United Kingdom (31), 33% had Type I diabetes, and 67% had Type II diabetes. Factors resulting in diabetes Type II developing (15), however, are the same as for people in the general population, those of family inheritance, obesity, old age, and lack of physical activity. Poorer blood glucose level control (31) was more likely with younger people either living with their parents or independently, and who were obese.

The prevalence of diabetes increases with age (30). In people with IDD aged 50 years and over (31),14% of the sample had diabetes, 17% of those had symptoms of depression, and 16% had symptoms of anxiety, but only anxiety reached significance on analysis. Depression and anxiety may have secondary biological effects, leading to glucose intolerance, and fat accumulation, further affecting diabetes control. Dysch, Chung and Fox (32) lamented the lack of qualitative literature for such a major health condition, demonstrating that although the people with IDD had some knowledge about their diabetes, there was also considerable confusion and uncertainty. Participants described the impact of their diabetes on them in terms of physical, emotional and social consequences. Cardol, Rijken and van ShroetensteinLantmande Valk (33) when interviewing people with mild to moderate ID and diabetes noted the following common themes.

- Feelings of loss with regard to food intake and choice.
- Having to do regular blood glucose tests and for some, to give insulin injections.
- Not feeling ill, yet having to check blood glucose levels, and worrying about the consequences of putting on weight.
- Unanswered questions to clinicians about their future.
- Apprehensive about asking questions at checkups.
- Wanting to self-manage but difficulties with understanding, motivation and special occasions.
- Issues affecting self-management: Lack of support to develop the skills, and impediments to making healthy choices about exercise and food when living with others not restricted by diabetes.

The following vignette illustrates the impact on FQOL when a child with IDD is also diagnosed with Type I diabetes.

Sam’s parents were told he had severe CP when he was only a few months old, with associated vision impairment. Although they lived 45 kilometres away from a unit specialising in supporting children with vision impairment and physical disability, his mother considered it worth the travel to attend the early intervention classes there, with the expectation he would be provided with transport once he was eligible to attend the preschool section. Unfortunately Sam developed diabetes Type I when he was three years old, and his blood glucose levels were difficult to stabilise, swinging widely from dangerously low blood glucose levels to very high levels. As it was medically unsafe to allow Sam to be transported unsupervised by an adult, and he lived well beyond the distance over which a support person could be provided, his mother transported him, staying for the day in the city rather than making a double trip. Sam being diagnosed with diabetes Type I has not only affected his QOL but also FQOL, as parents try to work out the best options for Sam, them as parents, and for his sibling. They have to weigh up the advantages and disadvantages of continuing to live where they have chosen, with Sam needing to be moved to a less appropriate educational facility closer to home, versus moving house to allow Sam to continue to attend the most appropriate educational facility for his needs.

Recognising the presence of pain

Parents have told the author of their frustration and despair when clinicians, especially medical and dental, either say the person with IDD cannot be experiencing pain because he does not say he has pain, or they say they have a high pain threshold and do not feel pain, therefore do not require pain relief. Although some people with IDD are able to state they have pain in some or all situations, many are unable to, but the observant parent or service provider will be able to notice the non-verbal indicators of pain, providing they know what to look for (13).

- She cannot express pain/has a very high pain threshold-I tend to know by her expression e.g. her face gets pale. Because of her high pain threshold she has to be watched carefully-I can pick up she's in pain but others e.g. doctor, dentist etc. cannot(13).

The following vignettes from parents, and in some cases the female with IDD, are grouped according to the nature of the disability, as there are some differences between the groups. In the sample of 95 females with IDD in a PhD study (13), 68% of the females were reported to have period pain with some or all periods. Although 60% could say they had pain when they were hurt or unwell, only 24% were able to state they had pain before and during their period, yet they had behavioural indicators of pain.

Pain in females with IDD and Down syndrome (DS)

Rather than females with DS being insensitive to pain (34), they express pain or discomfort more slowly and less precisely than people in the general population. A study of vocal responses of infants with DS (35) found they needed more stimulation to cause crying, and took longer to react. This lack of cry response increases with age, with children with DS over one year old not showing the visual responses of grimacing, limb movements, or breaks in respiration seen in typically developing infants.

The most common non-verbal indicators of pain observed in the sample were not moving, less active or quiet; seeking physical comfort and closeness; and crying moderately loudly. When hurt or unwell, 79% were able to say they had pain, but only 29% could say they had pain in relation to periods. More females with DS were able to point to or touch the painful area than females with IDD in the other groups (13).

- Rarely says she has pain, does not bend over, but moans whines or whimpers, eats less, not interested in food, does not smile, is less active and is quiet, more irritable and stubborn (13).
- Copes very well with general injury, does not react as much as a person without a disability would. Does get scared though. Reacts more to be scared than actual pain (13).

Pain in people with IDD and autism spectrum disorder (ASD)

Clinicians have expressed concern (36) that the professional and scientific literature, on which information to parents is based, states people with autism are insensitive to pain, with the potential for under-estimation of pain, and consequent lack of appropriate assessment and treatment.

The most common observations when the female with ASD is considered to have pain (13) are not moving, less active, quiet, and non-cooperative, cranky, irritable or unhappy.

- When in pain gives a small laugh, easy to miss and there is no further sign. Unwell, may be cuddly and want to be nursed, may be quieter, or show increased non-compliance with hitting out (13).

The following vignette illustrates the impact of pain on a child with ASD unable to communicate.

A mother presented with her eight year old son with autism and IDD because school staff were wearing leather arm guards to protect themselves from unprovoked attacks. His paediatrician had recently increased his risperidone, which his mother thought had actually made him worse. On questioning, he had symptoms of gastro-oesophageal reflux (acid flowing back up the gullet and causing pain). After treatment with anti-reflux medication, and reduction of his risperidone, within a month the feedback from his mother was that FQOL had improved significantly. Although his challenging behaviours were not entirely eliminated, he became calmer and more manageable, so they could take him to the local shopping centre again, and take him to family functions.

Pain in females with IDD and cerebral palsy (CP)

People with CP (37) are at greater risk than others for under-treatment of pain because of their behavioural idiosyncrasies such as moaning, changes in facial expression, sleeping patterns and patterns of play that are inconsistent and difficult to interpret because of physical difficulties. Additionally, society appears to value the comfort of children with CP less than for other children.

For females with CP in pain, the main observations were being non-cooperative, cranky, irritable or unhappy; moaning, whining or whimpering and making a special sound, cry or laugh (13).

- With pain from general injury cries or has a seizure (13).
- With general injury most people would find painful, cries, sweats, groans and is moody. Not able to state she has pain, but does point (13)

Pain in people with IDD

The main observations reflecting pain were not moving, less active, quiet; seeking comfort or physical closeness, and crying moderately loudly (13).

- If injured, occasionally laughs if it is mild pain, becomes agitated and laughs or sings with moderate pain, and screams and winges with severe pain (13).
- Something that should be extremely painful ie shut hand in door, burst eardrum, no reaction. Something small i.e. bump into something, cries with tears, yells (13).
- Her pain tolerance is quite high we think, but when in a lot of pain she will bite and hit herself, and has a hurt cry, different to other reasons for crying. With general injury is teary, sad, outbursts of anger when confused or scared, can be violent and break things, sleeps less (13).

The following vignette graphically illustrates the significant impact on FQOL when pain is not recognised.

A 38 year old nonverbal male with IDD had indicated headaches since his mother died two years previously. He had early morning wakening, outbursts of violence, punching his unwell father and carers, and damaging property. He was moved from his father’s home in a country town to a large city hundreds of kilometres away, and started on anti-psychotic medication which made him worse. A brain scan showed sinusitis (infection in the air passages around the nasal areas). He was commenced on antibiotics for the infection plus an anti-depressant. The headaches and aggression stopped within 48 hours, too soon for the anti-depressant to have started to take effect. Unfortunately he had side effects from the antidepressant and required hospital admission. In this case failure to recognise pain led to the man being moved away from his family and familiar community, impacting on his HRQOL, and FQOL.

High pain tolerance or minimal reaction to pain was highlighted by 26% of respondents in the PhD sample (13), but the author gained the impression that it may be the female with IDD not realising she needed to make others aware of her pain rather than not feeling pain, or not realising others will not know she is in pain if she does not indicate pain in some way, either verbally or non-verbally.

Lifespan issues

Clinicians who are not also parents of people with IDD generally do not have consistent longitudinal exposure to the same people with IDD, to understand that development generally continues albeit more slowly than their non-disabled counterparts. The clinicians’ only exposure to people with IDD might have been as medical students many decades previously, when many people with IDD were still living in institutions (8). As described in Brown and Faragher (8), they would not realise that people with IDD who have lived in the community all their lives generally have a much better outcome than those who have spent most of their life in institutions. Not recognising the potential for increasing lifespan (8), in part due to medical advances, clinicians may actively discourage parents from trying to maximise the development and QOL of their person with IDD. Unfortunately parents are given the impression their person with IDD will be a perpetual child, and nothing will change that. The person may be capable of more than the parents believe or have been told, so parents need to be supported to understand that carefully graded development of independence results in the best long-term outcomes and QOL.

If clinicians fail to recognise the increased longevity of many people with IDD (38), they will not encourage parents to plan for the longer term. The author does not doubt parent reports of comments made to them by clinicians, such as ‘he’ll never walk’, ‘she’ll never talk’, ‘he’ll be a perpetual child’ when she was told by phone that her precious first born eleven month old daughter would be ‘a vegetable so forget her and have another one’. In many instances the prognosis was incorrect, the children with disability did walk, or talk, and reach many early milestones albeit more slowly than children in the general population.

The risk when clinicians do not think a child has a worthwhile future is that medical procedures which would be routinely offered to children in the general population are withheld on the basis that the child has a limited lifespan, and limited potential. Failure to perform these medical procedures may in turn reduce the child’s lifespan, with death due to the effects of an untreated medical condition, not IDD. The child is often left to suffer painful conditions, often without adequate pain relief, as many clinicians believe erroneously that people with IDD do not feel pain.

When the current teenagers and adults with IDD and severe CP were young, parents were often told by treating medical specialists that their child would not live very long, so they should just make the child happy and comfortable. With better medical management, those children lived until the teenage years or more, but because life expectancy was considered to be short, behavioural difficulties, particularly hitting, grabbing and pinching, were not addressed in the early years. Some of the behavioural difficulties related to inability to communicate in any way, and not being told or shown what was going to happen to them, resulting in them trying to push away anyone or anything getting close to them.

The increased longevity became obvious to the author in her role as Medical Consultant for a program supporting students with IDD and invasive health care needs. In the 1990s, students with CP died from recurrent pneumonia in their early teens, but the advent of tube feeding changed that. As soon as a baby with IDD and CP was diagnosed with aspiration (food and fluid going into the lungs), and simpler measures such as correct positioning, pureed foods, and thickened fluids alone were not adequate, a tube was inserted into the stomach for feeding, markedly reducing the risk of aspiration. Those students in many instances survived to graduate from secondary school, a significant increase in longevity in the space of fifteen years.

Family quality of life (FQOL)

Reflecting on a House Manager stating it was unusual to see parents of a person with IDD still together, and remembering parents of many people with IDD encountered, many of those now live in single parent households. Mostly it is the mother who takes care of her children after her marriage or partnership fails, sadly illustrating one impact on FQOL of having a person with IDD in the family.

Institutions (8) provided holistic medical and allied health care for both people with IDD living there, and those who attended daily, only transferring them to hospital for major medical issues. Parents did not have to transport their child or adult to endless medical or therapy appointments, generally on different days, and keep an active or noisy person with IDD quiet and occupied for a length of time.

As introduced by Brown and Faragher (8), the institutions provided parent education and parent support groups, helpful for parents feeling isolated by their child’s disability.

The author can identify with other parents who described feeling part of a big family, important when parents often notice friends drop away once there is a child with IDD in the family, partly because the care of the person with IDD intrudes so much on leisure time.

Impact on family members when one person has IDD and associated health care needs

This information on impact on parents complements the writing on FQOL by Zuna, Brown and Brown (9).

- Having to repeat all the medical and developmental history over and over again to every new professional seen.
- If health care is provided in the public health system, there is the potential for lack of continuity. Inability to form trusting relationships with professionals occurs when there is high staff turnover or reallocation, or there is minimal attempt to offer the next appointment with a professional seen previously.
- Continuity is also a problem when agencies only relate to a specific age group, requiring transition to a new agency. This is particularly pertinent when many paediatric services only see the person with IDD until the age of 18 years, often coinciding with transitions in education, possibly leaving school and moving to adult services. Many people with IDD have multiple volumes of medical records, which do not usually transfer with the person with IDD, unless a health professional very familiar with the person's history writes a comprehensive discharge summary, to avoid significant information being lost.
- Having to arrange to be at home for the seemingly endless rounds of professionals, then having the professional cancel on the day, with the added frustration of some providing conflicting information or advice.
- Despite not having seen the person with IDD recently, some professionals do not seem to communicate with each other, even in the same agency, until a day before the next review meeting. Unless a professional, not having seen the person recently, is able to contribute meaningfully, it would be better to discuss possible future management with a team member who has, and is able to take the information to the review meeting.
- Professionals not following through on commitments made, and being difficult to contact. This leaves the person with IDD and family suffering the consequences.
- Parents may separate or divorce, leaving one parent, mostly the mother, to care alone for the person with IDD's health needs.
- Parents may remain together, but with one parent, more commonly the father, leaving all health care to the other partner. This may take the shape of working long hours when not necessary, or having many outside commitments.
- A supporting parent fortunate to have employment cannot be sure the taxi or bus transporting the person will arrive in time for the parent to get to work on time.
- If seeking employment, availability is often limited to school or day activity hours in order to be at home for when the person with IDD arrives home, or to be able to collect him or her from a service.
- The person with IDD may be unable to go to school/day activities if the trained carer is not going to be available, meaning the person with IDD has to stay home in the parent's care. In some cases, in order for the person with IDD to attend, the parent has to go in to provide the health care procedure required.
- If the person with IDD becomes unwell in school or adult activities, he or she has to either be collected by a parent, or an ambulance is called. If the latter, the parent still has to go to the hospital if the person is non-verbal, and if admitted the parent often stays the whole time when hospital staff do not know how to care for their person.
- Difficulty finding trained carers or respite accommodation for a night out. Support not able to be guaranteed too far ahead, but parents have to book the function in advance, costly to cancel.
- Whereas grandparents, other relatives, neighbours or friends might take the non-disabled siblings at times (9), very few people are confident managing the person with IDD who has health care needs, so

parents do not get those precious short breaks.

- With the current trend to generic health care for all including those with IDD, not all clinicians have the expertise to manage the person, or are apprehensive about it, not knowing how to relate to the person. After hours the person may be given temporary treatment, but the parent has to return in working hours for completion of the treatment.
- Being forced to abandon a holiday and return to care for the person with IDD. One young adult with tube feeds, when in respite regularly pulled his gastrostomy button out, knowing his long-term foster father would collect him or stay at the hospital with him.
- Not being able to spend as much time with siblings because of the time taken managing the health needs of the person with IDD, and less time for community contact (9).
- High costs of equipment, medication and travel for appointments reduce the amount of money available to use for other family members.
- A child with IDD but no health care needs is often able to attend before and after school care, and holiday care. However, the person requiring an invasive health care procedure may not be accepted because of the unavailability and extra cost of hiring specifically trained staff.
- Where there are two parents involved, only one attends functions with siblings. In a single parent family the parent often has to miss functions for the siblings.
- Parents report feeling like prisoners in their own home, feeling too tired to have visitors or go out, when the health needs of the person with IDD take up so much time. A number of parents report having been medically treated for stress, depression or anxiety.
- If the person has a medical condition which might require emergency management, such as prolonged seizures or Type I diabetes not consistently responding to emergency treatment, travel has to be by road instead of the faster plane.
- Reduced opportunities for parents to work or study, with both financial limitations, and the inability to attend regularly (9).
- Parents fearful for their son or daughter's future, and wanting to protect him or her from harm may actually increase vulnerability by being excessively overprotective.

Impact on siblings

This information complements the research results reported by Zuna, Brown and Brown (9).

- Feel cheated of quality time with parents. May cling to a parent more, realising it is one way to know if a parent has to leave unexpectedly to go to the person with IDD, and to be reassured alternative care has been planned for all siblings.
- One sibling said she was always scared if her mother took her to a netball match away from home, but then left for shopping before returning to collect her daughter. The sibling worried about her mother not returning, fearing her sibling with IDD had had a prolonged seizure and had been taken to hospital. Although other parents would have transported the girl home, she felt too embarrassed to ask them.
- Too embarrassed to invite friends over, or ask for the sibling with IDD to be kept away, and worry about being embarrassed out in public.
- Less family money available when the person with IDD requires expensive medications, equipment and therapies. If this limits being able to buy school uniforms or other clothes, go on school excursion and camps, or go out with friends, siblings may resent the sibling with IDD.
- Afraid to look forward to enjoyable activities such as birthday parties, outings, or holidays, when it could all be cancelled if the sibling with IDD's health needs are not able to be

supported by a carer, becomes unwell, or is admitted to hospital.

- Having to drive on holidays instead of flying if the sibling with IDD might require emergency management not able to be managed on a plane. Limited availability of respite also limits options for family holidays to ones the person with IDD could also manage. Growing up, many siblings are unable to experience the range of experiences enjoyed by families without a person with IDD.
- When the sibling with IDD has a condition such as epilepsy or diabetes requiring unexpected urgent transfer to hospital, if the parent meant to collect them is ever running late, they worry something has happened to their sibling.
- When the sibling with IDD stands out more, siblings need to be helped to respond to cruel comments from peers, and sometimes adults (9). Comments may be taken personally, thinking they are directed at their sibling with IDD.
- One sibling was upset by peers using the term ‘spaso’, thinking they were referring to her sister with IDD, at that stage in the same primary school. When she later used the same term in relation to a non-disabled student she was able to realise such comments were not necessarily directed at her sister. She then worked out how to cope with such comments directed at her sister by saying ‘She was born like that. What’s your excuse?’ By the time the bullying student worked out what she had said he was lost for a response, and left her sister alone.
- May either be expected to learn invasive health care procedures, or alternatively take them on to relieve the pressure on the parent, at a level of responsibility not appropriate for their age.
- Some siblings develop a fear of injections, having blood taken, or visiting hospitals, after seeing the sibling distressed by these.

Conclusion

Although each condition or circumstance is described in isolation in this article for clarity of reading, many families of people with IDD are facing all these issues concurrently. It is families who bear the brunt of other’s failures, such as agencies not being able to provide the promised carers. In these circumstances, FQOL can be significantly compromised.

Although many professionals and disability-related services are attuned to the needs of the person with IDD and the family, there are still many that are not. The author is reminded of such a situation. Due to commence kindergarten in the February, parents arranged the days of kindergarten attendance for their daughter with IDD to avoid clashing with her early intervention group, and health staff were rostered for her tube feed. Everything was in place, until the parent was contacted a week before to say the therapists from the disability service had just decided to change the day of the early intervention group. When the parent said the kindergarten days had been chosen to avoid clashing, but now would clash, the parent was told she had to choose between the two options!

A family may cope with one setback in regards to their person with IDD and health care needs, but they more commonly face multiple setbacks. At these times a poorly thought out comment from an uninformed professional can result in aggression or tears of frustration on the part of the parent, who then inappropriately gets the label of not coping.

People with IDD are encouraged, sometimes forced, to use generic services. This seems to be false economy if professionals in generic health services are not skilled or comfortable relating to a person with IDD. Although treating the person with the best of intentions, if early signs of illness or disease are not recognised at a stage when treatment is likely to be successful, the cost of late treatment would be significantly higher both financially and in terms of suffering. This not only impacts on the person with IDD, it also impacts on FQOL.

Recommendations

- Clear information should be provided at the time of diagnosis, about the disability or health condition, with a plain English one incorporating pictures for the person with IDD.
- Disability services, and in some instances health services also, should plan collaboratively to avoid conflicting planning or information being given to the person with IDD, family or caregivers.
- The needs of the family should be considered as a whole, with collaboration between funding sources where practicable, to avoid duplication of services or gaps, and to reduce the number of service providers the person with IDD and family have to relate to at any one time.

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Quality of life and older aged adults

Nancy S Jokinen, MSW, PhD[*]
School of Social Work, University of Northern British Columbia, Canada

Abstract

Older-aged people face inevitable transitions and life events as well as experience other age-related changes. A significant challenge to maintain quality of life also appears as people age and experience diminishing cognitive abilities associated with Alzheimer's disease and resultant increasing dependence on others for personal care and day-to-day activities. Extending diminishing social networks and the provision of formal services may become a necessity in supporting some older-aged adults. The cumulative effect of these changes and service provision potentially affects quality of life for both the person as well as their family as a whole. This paper explores individual and family quality of life as it pertains to older-aged adults including adults aging with an intellectual disability. It discusses select issues associated with fundamental concepts and principles of quality of life such as lifespan, choice and self-determination, and the role of social relationships. The paper concludes knowledge exchange between the essentially separate fields of intellectual disability and aging may lead to a better understanding and potentially enhanced quality of life as experienced by all older-aged adults and their families.

Keywords: Quality of life, aging, life events, Alzheimer

Introduction

Aging demographics, quality of life, and family caregiving are dominating topics of concern in public policy and service delivery in many countries. As Brown and Faragher (1) suggested quality of life is an often-used term with varying definitions. Yet there are commonly held tenets across these definitions that suggest a 'good life' constitutes an overall enjoyment of life, active and meaningful engagement with others, access to resources to meet needs, and a perception of control or autonomy over one's life.

Quality of life alongside aging is of substantial concern in the field of intellectual and developmental disability as well as in various other sectors charged with developing policies and providing services to

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[*] ***Correspondence:*** Nancy Jokinen, MSW, PhD, University of Northern British Columbia, School of Social Work, 3333 University Way, Prince George, BC, Canada V2N 4Z9. E-mail: Nancy.Jokinen@unbc.ca

older-aged adults and their families. Worldwide, demographic changes point to aging populations having tremendous implications for policy and practice. Increased longevity, lower fertility rates, changes in the structure of the family, coupled with migration from rural to urban settings for work put strains on all societies to meet the needs of a continually increasing number of older adults. While many developed countries have had a longer period to consider the implications of and respond to the needs of an aging society, other countries will be hard pressed to respond more quickly. Many of these countries will require policy and practice changes aimed at reducing poverty, preventing the onset of chronic health conditions, and addressing the needs of older-aged adults (2) in order to attain a quality of life with age.

This paper focuses on people aging with and without an intellectual disability. While various countries use alternative terms to denote an intellectual disability (e.g. learning disability in the United Kingdom or developmental disability in Canada), this term is used on an international basis to identify the condition. The American Association on Intellectual and Developmental Disabilities offers a widely accepted definition of intellectual disability (3).

Older-aged adults, with or without an intellectual disability, are a group of people with a wide range of skills and abilities, diverse living circumstances, and varied life experience. Generally, adults with an intellectual disability age similar to people in the general population although there are exceptions (e.g. people with Down syndrome experience earlier signs of aging than would be generally expected). Commonly, all people face significant transitions and life events (e.g. death of family or friends) as they age and age-associated physical changes (e.g. sensory changes, onset of one or more chronic diseases) that likely affect their quality of life (4, 5). Additionally, adults with and without an intellectual disability may live in poverty, or are at risk of living in poverty during old age, that affects health and restricts opportunities (2, 6). A quality of life approach must consider at a basic level the individual's realization of the necessities of life (7). Challenges to maintaining quality of life also arise if any older-aged adult becomes increasingly isolated with a diminishing of their social support networks or dependent on others for personal care and day-to-day activities because of the onset of a chronic health condition. Furthermore, maintaining quality of life is of particular concern in supporting persons with the progressive loss of cognitive and functional abilities associated with Alzheimer's disease or other dementias (8,9). The transfer of knowledge across traditionally separate fields of research and practice (i.e. intellectual disability and aging) can possibly serve to improve an understanding of quality of life and drive change that then better meets the needs of all older-aged adults and their families.

Many older-aged people in the general population live out their lives in community settings, actively engaged with others, and manage changes and transitions with support from family and friends. Yet, others struggle to maintain their lifestyles and a desired quality of life due to life events and age-associated changes. For a small number of older-aged adults who develop complex care needs in developed countries, it is often recommended they live out their lives in a facility providing aged care (e.g. nursing home) although this may not necessarily be what they want or that meets their needs (10).

This practice, of course, varies across countries as well as with ethnicity. Yet Canada for example, as a multicultural society with a public policy stance supporting home and community care, has a relatively high percentage of older people living in facilities that offer specialized care (7.1% of all seniors). This prevalence is not static across all age groups of adults aged 65+ rather it increases with age, peaking at 29.6% for those aged 85+ (11).

Adults aging with an intellectual disability, on the other hand, may have differing experiences in comparison to age peers in the general population due to their lifelong disability (e.g. childhood institutionalization, education, employment opportunities, and or lengthy involvement with formal social services). Traditional periods of transition (e.g. moving away from parental home, marriage, parental status, retirement) experienced by adults in the general population may also be atypical for adults aging with an intellectual disability (12). For adults with intellectual disabilities, aging can present unique challenges for the individual as well as their families and service providers (e.g. retirement may require availability of additional residential or alternative day supports; death or ill health of a parent caregiver prompting sudden relocation from the family home). Nonetheless, in both the fields, many human service policy and practice statements refer to and strive to enhance quality of life for older-aged adults.

This paper highlights quality of life as it relates to older-aged adults including adults aging with intellectual disabilities. It begins with a family vignette (13) that serves to illustrate circumstances that may challenge quality of life. Following that, the paper considers general trends in the literature from both fields of study regarding individual and family quality of life. The paper then focuses specifically on notions related to (a) lifespan, (b) choice and self-determination, and (c) the role of social relationships. These are fundamental areas of concern across the fields of intellectual disability and aging, and likely have profound impact on both individual and family quality of life.

The paper takes a critical view and raises questions about our approaches to the support and care offered older-aged adults. It concludes that knowledge exchange between the fields of intellectual disability and aging is indeed critical as expressed by others elsewhere (14). Furthermore, family quality of life as an approach may take on greater importance in forthcoming years within both fields of practice as the population continues to age and pressures on public services mount within a context of restrained economics.

Joan is 69 years old, divorced with children and grandchildren. She has two siblings; Eric, aged 68, has an intellectual disability and John, the oldest sibling, resides out of town. As children, Joan and Eric would often play together. Eric was then separated from the family for more than a decade as a youth when he was institutionalized and Joan had little if any contact with him during that time. They were reunited as adults when Eric returned to the community. Joan raised her children and worked full time until retirement. She was the primary caregiver for her mother and mother-in-law until their deaths and now feels a need to help support Eric. She and Eric live separately across town from each other. An intellectual disability agency helps manage Eric's monthly finances. Weekdays, a meal program also delivers him one meal a day. Joan says Eric is sociable; he often meets other tenants in the building's lounge to chat, goes out to hockey and baseball games, and is active in his faith community. Eric has complex health issues including diabetes, heart disease and emphysema. He frequently says he is "just fine" and agrees to things without understanding proposed treatments, prescriptions, or need for follow-up appointments. Joan also said Eric often mimics others giving an impression of competence. For instance, he cannot read yet while waiting for appointments appears to be reading newspapers or magazines. This has led to difficulties with healthcare professionals recognizing he may not fully understand explanations or instructions and needs support. Eric was discharged suddenly from the hospital three weeks ago and this left Joan scrambling for arrangements. Home health care was arranged - two hours a week for housekeeping purposes and a visiting nurse to bandage an open lesion that requires out of town surgery in the near future. Since Eric returned to his home, Joan says she has not had a day to herself. She is constantly tending to his needs. Joan thinks Eric may need to move into a nursing home, yet the costs of living there would severely restrict his opportunities to continue going out to sports events as well as associate with his friends – the other tenants at his current home. She thinks he may not want to move although she is unsure how long she can actually keep up with supporting Eric as is. (The names of individuals used are pseudonyms)

In this vignette, Joan and Eric apparently encounter struggles to maintain their quality of life. It is important to keep in mind their situation as some of the main tenets associated with quality of life – lifespan, choice and self-determination, and the role of social relationships - are discussed later in this paper.

Consider how their early life experiences influenced their later life circumstance; what choices might they have, given their current situation; the impact on both their relationship with each other as well as others; and, moreover, how might we support Joan and Eric to maintain their individual and family quality of life as events unfold?

General trends in quality of life literature and older-aged adults

Looking across the literature, individual quality of life has developed in both the fields of intellectual disability and aging. The general trends suggest overlapping thoughts in a number of areas, offering some commonality of issues and concerns between the two fields. Yet there are differences. Generally, these essentially separate fields of study seem to agree that quality of life can be considered at various levels – at the individual, organizational, or population levels – and that it is better understood as a multidimensional construct consisting of various domains of life known through both subjective and objective measures (15,16). In terms of family quality of life, the field of intellectual disability extended the work on individual quality of life to address that experienced by the family as a whole (17). Within the field of aging, although much has been written and reported about family carers, this literature tends to be particularly concerned with ameliorating caregiver stress and burden. Brief select highlights of the literature from the two fields (intellectual disability and aging) are now offered in the following to illustrate some of these similarities and differences.

Individual quality of life

Individual quality of life in relation to persons with an intellectual disability is a field of study with numerous references reporting theoretical thinking, studies and projects. The field has developed a holistic framework with principles and key concepts that have been detailed through both research and consensus work amongst researchers, families, and service providers (16). Many quality of life research projects, however, have involved younger-aged persons with an intellectual disability (e.g. teen-agers or young adults) and or their parents (primarily mothers) with comparatively fewer reports (18-20) concerned with older-aged individuals despite the unique challenges an aging population poses for the intellectual disability service sector.

Often the quality of life research concerned with adults aging with an intellectual disability refers to the person having restricted opportunities (e.g. living with aged parents) and choices (e.g. in where to live) as well as the influence service attributes potentially have on the quality of life. For instance, Higgins and Mansell (21) noted conditions in small group homes provided by intellectual disability service providers, and the supports offered therein, might be associated with improved quality of life as compared to other residential services for older-aged adults in the general population. Quality of life has also been expressed as a concern in supporting persons with intellectual disabilities who develop dementia (22,23) and, indeed, small group environments may well be better suited to offer conditions facilitating quality of life when individuals and their families are confronted with dementia (8,24).

Some early reports in the literature do indeed refer to dilemmas in maintaining quality of life as people age. For example, Orly and Cox (25) considered health, aging and quality of life while Janicki (26) and Brown (27) discussed limitations placed on choices because of physical changes or the onset of chronic conditions. In many individual quality of life assessments, health is often referenced within a *physical well-being* domain (28). Although health conditions are certainly topics of keen interest in the literature on adults aging with intellectual disabilities (29), the focus tends to be on practice and policy versus examining the impact of health on quality of life as people age.

A comprehensive measure of quality of life in the field of intellectual disability considers objective as well as subjective evaluations of multiple domains or aspects of life. Although variously named, these domains and sub-domains capture different aspects of life. For example, Brown and Brown (7) refer to a quality of life framework with three core domains of *Being, Belonging* and *Becoming* with 9 sub-domains (physical, psychological, and spiritual *being*; physical, social and community *belonging*; and practical, leisure and growth *becoming*. A questionnaire is used to evaluate each sub-domain specifically (e.g. the physical being sub-domain queries appearance, exercise and fitness, hygiene, nutrition, physical health and sexual life) on essentially four key aspects (importance, satisfaction, opportunity, and self-determination) (p. 127-128). Alternatively, Schalock and Verdugo (28) identify eight domains (i.e. personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being and material well-being) clustered within three higher level categories of quality of life factors (i.e. independence, social participation, and well-being). Within this framework, there are ideal indicators for each. For example, within the self-determination domain, key indicators are "autonomy/personal control, goals and personal values (desires, expectations), [and] choices (opportunities, options, preferences)" (p. 44). Several notions about the measurement of quality of life are worthy of noting. Regardless of labels, measurement of quality of life should consider the totality of various aspects of life; variation as to the importance of any particular domain should be assigned by the individual; and interventions on any one aspect of life will likely have a ripple effect on other domains (7).

Within this field, however, no individual quality of life measures were found specifically designed for use with older-aged adults. The tendency seems to be the use, or adaptation of, measures that are applied across the lifespan. While the domains of life appear relevant, it would seem logical that key indicators need to consider age. People's perceptions and priorities change over the lifespan (30). For example, many of these instruments refer to notions of independence and autonomy and, certainly, these are critical concepts associated with quality of life. However, what do these mean in the context of older age? Additionally health, or physical well-being as another domain example, should possibly take into account concerns about barriers and issues (e.g., reliance on others, knowledge and understanding of aging) in order for older adults with intellectual disabilities to maintain health and have access to timely, appropriate health care.

In contrast, as might be expected, there is a plethora of literature in the field of aging pertaining to individual quality of life and older-aged adults within the general population. Predominately, this research developed taking a *health-related* quality of life approach in relation to an array of specific diseases or conditions associated with older-ages, as influenced by the 1948 World Health Organization's change in defining health (15). In part, this work also arose with advances in medical science (including heroic measures to save the lives of critically injured people) that held the possibility of extending life and a need to evaluate these interventions within a context of 'a life worth living'. Yet the notion of quality of life and taking into account individual perceptions is viewed as a 'gold standard' measure for health services and that it incorporates a holistic perspective comprised of multiple domains of life (31). Furthermore, we see from this literature that perceptions of what is important for quality of life changes over the life course whether through a maturing process and the development of differing viewpoints or through shifts in priorities based on life experience (30).

That said, in a review of the literature, Halvorsrud and Kalfoss (32) found most quality of life studies pertaining to older adults in the general population lacked a conceptual framework for quality of life and often lacked distinction between a holistic and health-related quality of life approach. Furthermore, there does not appear to be consensus on the measurement of quality of life for older-aged adults although several multi-dimensional quality of life measures specifically in relation to older age have been developed. However, most of these measures rely solely on self-reports instead of taking a comprehensive approach to include objective measures (15). These instruments are often used in research and include, as examples, CASP-19 (33), WHOQOL-OLD (34), and Older Person's Quality of Life Questionnaire (OPQOL) (35). Brief descriptions of each are now provided to draw out some of the similarities and differences with the field of intellectual disabilities, in particular those pertaining to the domains of life.

The CASP-19 has four domains: control, autonomy, pleasure and self-realization. The name CASP is derived from the first letters of each domain and 19 refers to the number of items in the scale. Control, for instance, is measured using 4 items ("my age prevents me from doing things I would like to do; I feel that what happens to me is out of my control; I feel free to plan for the future; and I feel left out of things") rated on a 4 point Likert agreement scale (36,37). The WHOQOL-OLD, developed in conjunction with the World Health Organization (WHO), initially contained six aspects of life relevant to older adults (sensory abilities, autonomy, activities - past, present, and future - social participation, death and dying, and intimacy). These are measured using four items each on a 5 point Likert scale. Given its length (24 items) and the propensity to develop shorter scales that require less time for both the administrator and respondent, Fang and colleagues validated 3 short form versions of the WHOQOL-OLD (38). Lastly, the OPQOL was developed with input from older adults and consists of 35 items. In addition to asking older adults to rate their overall life, it includes seven aspects of life (health, social relations, independence/control/freedom, home and neighborhood, psychological and emotional wellbeing, finances, and leisure and activities). These are rated on a 5-point Likert agreement response scale. Research established the psychometric properties of the instrument and it was, comparatively, found more applicable to diverse populations of older people than the WHOQOL-OLD and CASP19 (35). As with the WHOQOL-OLD, a shorter 13 item version of the OPQOL was developed following similar procedures to the original (e.g. asking older adults to prioritize aspects of life to retain in the short version) (39).

In summary, both similarities and differences exist between the fields of intellectual disability and aging in regards to individual quality of life. Both fields have developed a holistic approach to quality of life with various domains that include overlapping notions such as autonomy and self-determination. Similarly, both fields also seem to lack specific reference to the spiritual needs of older adults in scales used to measure quality of life. Yet, the WHOQOL-OLD's (38) inclusion of death and dying as well as home and neighborhood domains suggests some differences. Further difference is apparent in the design of specific instruments for use with older adults. The field of aging has developed such instruments for measuring quality of life in older adult populations as well as shorter versions of these tools to reduce the administration time. The field of intellectual disabilities apparently relies on the use, or adaptation to some degree, of existing measures instead of pursuing measures designed for older ages. The questions become do the domains sufficiently cover key aspects of life, as people grow old, and are specific age-related instruments necessary? The exploration of individual quality of life within fields of intellectual disabilities and aging are essentially separate, each with their own strengths and weaknesses. Would establishing common ground and then initiating joint efforts further understanding that can be applied in both fields of practice?

Family quality of life

Worldwide, families are involved in supporting older-aged adults with and without intellectual disabilities (40,41). In terms of older-aged families, the literature from the field of intellectual disability points to the unique needs and dilemmas faced with advancing age (e.g. future planning for parents and sons or daughters with intellectual disabilities who co-habitat). Similar to work in the field of aging, much of the early work, however, emphasized stress / burden of family caregivers and the negative aspects of disability on the family (13). The notion of family quality of life grew out of the work on individual quality of life to take a more balanced approach; opening opportunities to examine both the challenges as well as rewards experienced by families of persons with intellectual disabilities. A thorough review of the development of family quality of life concepts and principles is detailed elsewhere (17). Zuna, Brown and Brown (42) also provide historical context in addition to detailing a support based framework to enhance family quality of life.

Essentially, two main initiatives have undertaken the development of *family quality of life* as a field of study. The Beach Center for Disability's work has focused their work on families of children with disabilities (43) and identified five family quality of life domains as well as having developed assessment scales. The second major initiative is an international project (44) that has developed and utilized the *Family Quality of Life Survey* that incorporates 9 domains of life (45). This survey has been translated into a number of languages and used with families of both children and adults with intellectual disabilities as well as with families of children without disability (see for example 46). For further details on both these initiatives refer to Zuna, Brown and Brown (42).

While the preponderance of family quality of life work and literature, has reported on younger-aged families, several works have focused on older aged families (13,47). In both these cited works, the *Family Quality of Life Survey* (45) was adapted, with permission of the authors, and used following interviews or focus groups to substantiate qualitative data. In adapting the *Family Quality of Life Survey* (45), a number of key aspects can be considered (e.g. whether or not family members live together, self-reports of chronic medical conditions, and the occurrence of any major life event within the last year) (13). These would serve to bring to light any potential impact such circumstance might have on family quality of life.

While family quality of life work appears to be at a very preliminary stage in regards to older aged families, there are a number of associated core concepts and principles relevant to older ages. These include recognition that:

- a *holistic* approach reflects on the relationships between and amongst family members, and their individual and collective interactions with the world beyond the family;
- a *lifespan perspective* acknowledges each period of life is interconnected and has influence on opportunities, choices, and decision making;
- *variability* exists, each family is unique in composition, values, needs, and concerns;
- the importance attached to aspects or *domains of life* varies across families;
- the *dynamic* nature of family quality of life is influenced by changes in perceptions held by either individuals or the family as a whole and/or alterations to the environmental context within which the family lives; and
- *family self-image, opportunities, and choices* empower families (48).

The notion of family quality of life, as known within the field of intellectual disability, was not found within the literature pertaining to aging and older adults in the general population. Within this body of literature, the importance of family and familial support is certainly recognized and it acknowledges there is much to learn about the role played by family particularly in regards to specific situations that may be trying (40). Rather than consider the family as a whole, as in a family quality of life approach (7), this particular stream of research and reports on families pertinent to aging in the general population seems to persist in dichotomizing family members into primarily caregiver or care recipient roles. Considering the family as a whole may add substantially to knowledge and have profound implications for policy and practice in the forthcoming years.

Core concepts and principles

In the following sections, core concepts and principles associated with quality of life from the field of intellectual disability are explored. Specifically lifespan, choice, and the role of social relationships are used to frame this discussion (1). These are key aspects in relation to quality of life and older-aged adults. In part, questions are raised about our understanding of these in relation to quality of life in research and practice with older-aged adults.

Lifespan

One of the features of quality of life in the field of intellectual disability is its attention to lifespan (1). In essence, this acknowledges the influences early life can have on later life as well as that people can and do change and learn over the life course given opportunities. Early life circumstances, therefore, do not necessarily predict quality of life to come in later years and individual learning and change that occurs over the lifespan likely influence change to the quality of life experience in the moment. The notion of quality of life has also been linked with and considered an overarching goal of successful aging (49).

While early life conditions (e.g. impoverishment) and lifestyle choices (e.g. excessive alcohol consumption, poor diet choices) can affect an individual’s later life - physically, mentally and emotionally - later life can also bring about profound changes (e.g. role change, increased risk of chronic disease) that influence perceptions of quality of life. Furthermore, society’s medicalization of old age needs to be balanced (50), with a fuller understanding developed about the interplay of various aspects of life that may counterbalance previous life experiences and the onset of potentially detrimental events in late life. What conditions can be set in motion to help maintain or even enhance quality of life with these lifespan issues? While quality of life trajectories tend to predict declining quality of life with advancing age, a number of factors apparently influence this decline (51). For example, "…enhancement of QOL [quality of life] in older ages can be achieved by improving the psychosocial circumstances of older people and ameliorating the functional limitations associated with age-related declines in health" (p. 1307).

Several other questions also arise. In the measurement of quality of life, for instance, are the instruments sensitive to or able to account for life events or transitions experienced by older-aged adults? In terms of adults aging with an intellectual disability, many likely have atypical experiences of life events and transitions compared to adults in the general population (5,12) as well as psychological problems (52) and potentially increased hospital emergency use (53) as a result of life events. Additionally, how do quality of life frameworks 'fit' with notions of healthy aging and age-friendly communities (54) evident within the literature on older adults with the general population? It seems likely they are complementary though some detailed analysis would serve to confirm this as well as further notions about factors contributing to or detracting from quality of life. Finally, a lifespan approach must also include the end-of-life; the last act of life is dying. Quality of life work should therefore include the possibility of a 'good death', what constitutes it, and how it is supported on an individual and family level. In part, hospice and palliative work within the general population can be drawn upon as well as specific issues raised in relation to end of life care in dementia as it affects persons with intellectual disability (8,22).

As Brown and Faragher (1) suggest there is a need for longitudinal research to fully understand changes across the lifespan to facilitate development of strategies to support quality of life over the course of a lifetime. This information takes on greater and more urgent importance because of worldwide changing demographics. Literature in the field of aging also suggests quality of life differs for older-aged versus younger-aged people and perceptions of quality of life and priorities of what matters change with age and social, economic and cultural context; and events encountered along the life course impact quality of life (see as example 30). While many of these events and transitions can be anticipated, some are planned for whereas others are not (12). The temporary or prolonged impact life events and transitions have on quality of life has yet to be fully realized.

Choice and self-determination

Choice and self-determination are cornerstones in a holistic quality of life approach, appear linked to notions of independence, and are prominent themes in practice with persons with intellectual disabilities as well as with older-aged adults in the general population. Edgerton and Gaston in chronicling the lives of older-aged adults with an intellectual disability noted their search for well-being "… involves an ever-shifting calculus that attempts to balance freedom of choice against the need for the help of others" (20, P.273). Others (26,27) have also pointed to challenges in maintaining quality of life and limitations placed on choice and self-determination when age-related changes occur and support needs increase. In reality, a number of factors (e.g. social relations, life circumstance, resources) may limit to some degree choices for all people (26). Yet fundamental issues involving choice, autonomy, and self-determination appear accentuated in older populations. From the field of aging, for example, several systemic barriers (e.g. geographic location, economic resources, and caregiving responsibilities) were found to constrain choice for older-aged adults to be socially engaged, thereby, potentially experiencing negative influences on quality of life as well as on their ability to attain healthy aging (55).

In both of these fields of study, many policy and practice statements espouse the importance of choice and self-determination; a sense of control over one's life and a need for environments to support self-determination. Yet, an individual's preference or choice may conflict with other family member priorities, it may be contested as risky, or fall outside a particular service provider's perceived obligations (56,57). Within both fields, there are also concerns about proxy decision-making and decisions made on behalf of another in 'their best interests', particularly with respect to autonomy at the end of life (58,59). Somewhat differing views have emerged about how choice may be applied within the respective fields of intellectual disability and aging in the general population. Brown and Brown's (56) example from the field of intellectual disability and Gurland, and colleagues model (60) from the field of aging are highlighted in the following to show some of these distinctions.

Although not specific to circumstances arising with age, Brown and Brown (56) review and consider the concept of choice as applied within the field of intellectual disabilities. From this perspective, two fundamental aspects of choice are the availability of opportunities and the act itself of choice making. Critically, having *opportunities* involves the extent of opportunities (the options) and the person's familiarity (experience) with those options.

Choice making at a very basic level may simply be indicating 'yes' or 'no' to an option, while in other situations there may be several options from which to choose. People with intellectual disabilities are often thought to have limited opportunities and lack experience, therefore, are limited in choice making by others. Yet choices occur in everyday life and Brown and Brown speak to the building of experience to enhance choice-making for all people regardless of level of disability. They also suggest professional and ethical dilemmas may arise in regards to choice if others (family or staff) perceive the choice made by an individual as not being the 'best' choice. How do these notions relate and impact an older adult and their family and the quality of life that they experience?

In the field of aging, Gurland et al (60) offer a model of choices and choosing amongst choices identified as the c-c process that could be employed within an interprofessional team work approach with older-aged adults to enhance quality of life particularly within a health care setting. A number of key tenets on understanding the c-c process to assist with the process are forwarded. Briefly these include:

- Ensuring information about the choices is accurate and complete, yet tentative.
- Providing the information in an atmosphere free of time constraints and distractions
- Presenting alternatives in an ongoing process including benefits and drawbacks as they emerge
- Guiding choices in a direction that reduces risk and harm
- Acknowledging people vary in their decision making comfort and capacity
- Considering the context within which choices are offered and made
- Providing feedback and having discussions are an integral part of choices; changing perceptions and capacity need to be identified and queried.
- Recognizing the needs of caregivers are of equal importance

Gurland and colleagues also warn of a threshold beyond which a person might become overwhelmed with unlimited or multiple choices. Situations such as this may lead the older adult to either disengage from the process or be dissatisfied with any choice made. Challenges within the c-c process also occur because of aging, poor health, and environmental factors associated with long-term care residential settings (e.g. who they might have to share living quarters with).

Choice of one option over others indicates an individual's values and preferences and should be respected thus promoting a sense of autonomy and self-determination. Although coincidentally involving risk, choice-making provides opportunity for learning (7). Housing and relocation, is an example that helps illustrate some challenges inherent in choice and self-determination faced by older-aged adults and their families.

What are the housing preferences and options for older-aged adults and their families? If older people live alone, will they continue to manage with age? Are their homes 'age-friendly' (e.g. stair-less versus multi-level) and located in a neighborhood with easy access to amenities? If residing with family or within a residential service, will this arrangement continue indefinitely? What say will the individual as well as the family have in considering alternatives and, lastly if relocation is required, will it be managed in a planful (proactive) or demand/need (reactive) manner (12)? Perhaps one of the most challenging circumstances faced by people is the possibility of losing their ability to choose and that sense of control over their life. This is most evident with the onset of dementia, whether from Alzheimer’s disease or some other cause. It is a dismal prospect to know incapacity and full dependence on others looms. Early detection of dementia, therefore, provides an opportunity for advance planning by the individual as well as service providers and the development of skilled and knowledgeable caregivers (8,9).

A proactive stance that includes support focused on the person living life to the fullest versus an emphasis on disease, deterioration and dying may possibly ease individual distress and help maintain quality of life despite the challenges. Choice, opportunity, and decision-making go hand in hand and are fundamental to quality of life (56). Supporting individuals to be in control of their life requires skilled staff and an organization culture that values principles and strategies that promote choice and choice making (60). Addressing systemic barriers that unnecessarily limit choice in older-age is also required (55).

Role of social relationships

Social relationships have a profound influence on the quality of life experienced by all people and the nature and extent of these relations are critical features to consider.

In this section, another vignette illustrates the plight of one older-aged family (61) and the key role social relationships, or the lack thereof, likely played in the outcome. This is then followed by a discussion of some key aspects of social relationships in maintaining and enhancing quality of life.

In 2007, a community’s newspaper reported that an 89-year-old widow and her 45-year-old daughter who had Down syndrome had died. They had lived together in their home and neighborhood for decades, yet apparently became increasingly isolated. A few years beforehand, the mother withdrew her daughter from a program provided by a disability service without explanation. A neighbor reported seeing the daughter outside the home waving about a week prior to discovering the bodies although no one went over to check on them at the time. The police attended the house after receiving a call indicating concern about seeing no activity at the home and lights uncharacteristically left on all night. According to the news report, the mother died first and the daughter likely died of starvation several days later. Extended family was located living overseas.

While this might appear to be an extreme example, it is appropriate to consider how any older-aged adult or family with few if any social relationships outside the home may be vulnerable to a similar fate. As people grow old, social isolation and loneliness can be particularly troublesome. A dwindling social network with the deaths of family members and friends, a lack of general social contact, and feelings of dissatisfaction with one’s social relations or lack thereof can have a detrimental impact on health and wellbeing (62).

Some key aspects of social relations in maintaining quality of life

The most basic and early-forming social relationships begin within the family. Family provides a sense of belonging and inclusion within the most fundamental social group. Family relationships are important for all older-aged adults, with and without intellectual disabilities, and familial caregiving plays a crucial role in support of older adults in many countries. Family relations, however, should not be idealized and, indeed, people may have significant others who they perceive to be family but would not necessarily be considered legally family (7). For instance, some older-aged adults with an intellectual disability have severed biological family ties due to institutionalization that may or may not have rekindled in later life. Family relations for people, with and without disabilities, may also became estranged or strained for a variety of other reasons (e.g. abuse, violence, behavioral challenges, and alcohol or drug addiction). People may go on to develop ‘family-like’ relations that are long-standing, close, and nurturing. For adults aging with intellectual disabilities, once institutionalized and repatriated to their former home communities, family members may no longer be living and established friendships developed within the institution may be lost.

Maintaining such forged friendships is a critical aspect in maintaining quality of life when older-aged adults relocate for whatever reasons.

Engaging in activities outside of the family such as through volunteering or being involved with various groups or faith communities provides opportunities to share interests, build personal social networks, and potentially develop mutually supportive relations. As people age, their social relationships certainly evolve, change, and include others 'outside' the family which contribute both to individual as well as family quality of life (7,13). A family quality of life approach taken with older-aged adults that embraces a self-definition of who is considered "family", therefore, serves well and acknowledges families take many different forms and includes significant others in a person's life (63,64).

However family is defined, many adults aging with intellectual disabilities may be embedded in their family's structure and context; always being a part of the family, having close sibling relations, and sharing time together. These family relations appear to be maintained or enhanced by regular routine-oriented contact and shared activities that occur over the course of everyday life and on holiday occasions (13). Interestingly, sibling relations are also one of the longest lasting familial relations that hold the possibility of mutual support in later years. These relations apparently wax, wane and potentially rekindle over the course of life and influenced by life circumstances (e.g., geographic location, work, and other responsibilities) (13,65).

Familial support is also an integral aspect of family relationships. Parents, siblings, adults with an intellectual disability as well as other extended family may all be involved at one point or another, and to varying degrees, in providing mutual support (emotional, physical, and practical). Yet this support may go largely unrecognized by formal service providers (13). Reciprocity in familial relations is a key aspect for consideration and reported on within both fields of study. Jokinen (13) and others (66) have noted reciprocity between older-aged parents and adult children with an intellectual disability. In the general population, a cross nation study of parent-offspring relations noted intergenerational reciprocity as important and those older-aged parents who helped their children more than were helped by their children reported higher levels of life satisfaction (67). This notion of giving more than receiving seems important to older adults and possibly offsets a common perception of becoming a burden to family in later life.

Support from family, friends and neighbors is particularly helpful when older adults face the challenges of key life events (e.g., death) and transitions (e.g. relocation). Formal services are often only contacted for assistance when transitions become problematic, complex, and or otherwise pose difficulties (4). In spite of the knowledge that has accrued on family caregiving, family involvement in transitions experienced by older adults (e.g., to a care setting or to a higher level of care) is not well understood (12,40). Yet, a change in residence or relocation can disrupt and likely changes the nature of older adults' social networks (68) that, in turn, challenges quality of life. Social engagement is a means to build viable social networks that can provide emotional and practical support. Social engagement, however, may be challenged by factors beyond the individual's control (55) and, alongside advocacy efforts, nontraditional avenues of support also need to be considered (for example the use of the internet as means to attain social support in 69).

The individualized nature and context of social relations and support (e.g., culture, location, and policies that support or impede family involvement) are necessary considerations in providing effective interventions to support both individuals and families (70). In looking back at the vignette that began this section, what interventions might have averted this tragedy? In discharging an older-aged family from a service, should there be some responsibilities to ensure the existence of a sound social network of support? As neighbors, should we keep a watchful eye out for the older-adults and families living in our neighborhoods? In some localities, delivery and utility people frequenting neighborhoods keep an eye out for troubling signs (e.g., mail or daily newspapers left uncollected) that might indicate people need help. Should this type of protocol become widespread given our aging population? The World Health Organization (2) forewarns of aging demographics, changing trends in family structure and support, and the increasing numbers of older adults living alone. Clearly, there is a need for action in policy and practice to support and enhance social relationships amongst older adults and their families, however defined.

Conclusion

Demographic studies support expectations of a longer life than experienced by previous generations. What remains is a question of how that life will be experienced as we grow into older ages. Our images of aging and older adults vary and are diverse. To a ten year old, anyone thirty years of age is old. To a fifty year old, it might be someone aged seventy. Our images seem to fit along a continuum of seeing older people as frail, helpless dependents requiring a formal system of care through to vibrant contributing members of our social communities.

Older adults with and without intellectual disabilities are a heterogeneous group with differing values, preferences, personalities, interests and abilities. Their life experiences and circumstances also differ. Given that, what constitutes quality of life for older adults and how might we support maintaining or enhancing quality of life? Is it, in part, tied to notions of 'aging with grace' or 'dying with dignity'? If these are desirable conditions, how do we promote their existence? How might we counter the notion of becoming a "burden" in older age that appears to be such a common perception in western societies? In addition, some thought must be given to the predominant model of support provided to older adults who require assistance beyond a limit of a few hours per week when preference and choices are to remain living in their homes and community. How can we better support family members to continue meaningful relationships and support their varied roles in caregiving of older-aged adults?

This paper focused on individual and family quality of life as it applies to older-aged adults, including adults aging with intellectual disabilities. It highlighted pertinent literature from the fields of intellectual disability and aging then offered discussion on key concepts and principles associated with quality of life – lifespan, choice and self-determination, and the role of social relationships. In doing so, it pointed out some of the similarities and differences in the respective fields and posed questions to prompt critical reflection. Cooperation and collaborative work between the essentially separate fields of intellectual disability and aging will surely enhance our understanding of the factors that influence quality of life in older-age and improve the ability to put this knowledge into practice. An outstanding question remains; who will take the initiative to bridge the fields in terms of quality of life?

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Incorporating the concept of quality of life in individual support plans

Nuta Yisrael Shurack[*], **BA, BSW, MSW(c) and Cynthia Roling, BA**
Milieu Family Services, Burnaby, British Columbia, Canada

Abstract

This paper provides an overview of the transformation in how Milieu Family Services engages in person-centered and strength-based goal planning. The paper highlights the importance of aligning the input, throughput, and outcome/output sections of the Individual Support Plan (ISP). The *input portion* of the ISP aligns the support needs that are both *important to* and *for* a person. *The throughput section* utilizes a quality of life (QOL) framework to align specific support strategies for each of the individual's identified goals and those support needs that are *important for* the individual. A support objective is chosen and applied to each support strategy to create a benchmark for achievement and to provide clarity. The *outcome/output section* of the Plan focuses on the impact of the support strategies on anticipated results and hence each QOL domain. Based on these three components of the person's ISP framework an easy to read, user friendly 2-3 page Staff Action Plan as well as a Personal Network Plan are developed. A 1-page My Support Plan is created and tailored for the person served using modified information and pictures (where applicable). The paper concludes with a discussion of how these changes have impacted the culture of the agency.

Keywords: Quality of life, planning, family

Introduction

The driving force behind the daily operation of Milieu Family Services is the mission statement, which reads, "To empower and support people as valued, contributing citizens in communities". This compels us to foster a culture that is committed to personal empowerment, person-centred support, and building sustainable relationships within communities. Personal empowerment reflects and addresses a sense of competence, a sense of relatedness, and a sense of autonomy (1). The empowerment mode, which teaches and fosters interdependence, is strength based

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[*] ***Correspondence:*** Nuta Yisrael Shurack, Regional Service Coordinator, Milieu Family Services, 201-4300 North Fraser Way, Burnaby BC, V5J 0B3 Canada. E-mail: yisrael.shurack@milieu.ca

and has the goal of creating the ideal conditions for each person to overcome barriers in the community and set the stage for there to be increased inclusion and a more accessible community. Person-centred support looks at each person served as unique and valued for their qualities and gifts (2). Cultivating relationships within the community focuses on building capacity, not working independently and building relationships with the people we serve and the community they live in. Our commitment to families and the people we serve is that support services should be directed and focused on their wishes (whenever possible). Being grounded in the above-mentioned principles sets the stage for the transformation we have gone through over the last two years.

We find that it is important to emphasize that this paper is based on our ‘lived experience’ over the last few years. This experience has propelled us to closely examine the nature of the support we provide, the impact of that support on individuals’ lives, and how we can most effectively facilitate person-centred goal planning so that effectiveness becomes standard and foreseeable, rather than coincidental. In this paper the reader will find key points of our journey from using a tool called Personal Goal Planning (PGP) to Individual Support Plans (ISP).

The paper includes a description of how the agency aligned its services and supports and how it has modified its input, throughput, and output sections the ISP to become more effective in terms of enhancing personal outcomes. We also discuss how we are now placing greater emphasis on staff reporting, the importance of support strategies, and how monitoring the impact of supports is not achievement based, but about enhancing personal outcomes. The paper concludes with a focus on how the ISP and associated changes have influenced the culture of the agency.

Applicability within diverse populations

We believe that the applicability of Individual Support Plans is not restricted to individuals with a developmental disability or to a specific culture, creed or religion. We have implemented the use of ISP’s in other aspects of our agency and have been met with similar success and excitement. Currently we are using the same format (although a different assessment tool) with youth at risk, families seeking counseling and mediation, and youth transitioning between youth services and adult services. Because an ISP is focused on support strategies and monitoring the impact of the support on a person’s quality of life, utilization is extremely flexible. Focusing on support strategies, as noted above, places leverage in the right areas so that person’s goals can be achieved and QOL maximized. The ISP framework can be easily modified to meet the criteria of different populations and different assessment tools without losing the focus on the QOL.

It is interesting to note that the SIS has been translated into many different languages and is currently used in a variety of countries. A study was conducted as to the applicability of the *Support Intensity Scale (SIS)* (3) with individuals with a mental health issue as opposed to a developmental disability and the findings were very successful with regards to goal planning and support application (4).

One of the main reasons why an ISP can be used with a variety of groups is its holistic nature and focus on the multidimensionality of people and families (1). The ISP focuses on all aspects of the person and therefore can easily shift between different types of people. Often marginalized groups of people are given access to specific services as outlined by a government or agency. Sometimes that support can be distributed disproportionately and services that they specifically need may not be provided. An ISP can help decipher what support is needed and where, so that appropriate goals and timelines can be made regardless of services available.

Agency alignment

An important step in changing the way we facilitate goal planning included aligning our agency to the following eight core Quality of Life domains: personal development, self-determination, interpersonal relations, social inclusion, rights, and emotional, physical, and material well-being. This included multiple steps and changes that needed to take place. We had taken part in a project entitled the, "My Life," survey which gave the agency direct feedback from individuals served (either by them or by proxy) on their quality of life, according to the domains, of the persons served (5). The "My Life," survey became a report card for what we wanted to improve and change (5). It was catalytic in that it propelled us into a shift that we very much needed to make. It gave us a clear direction so that we could coordinate our movement into an action-oriented evidence-based practice. Though we saw success within our current system, we lacked consistency and therefore we were only seeing islands of success. Furthermore, our approach was not standardized. We knew what the recipe for success was, but needed to act consistently as an agency to achieve the success we truly strive for: continual increased quality of life for the people we serve.

Over 18 months we made significant modifications to our policies and procedures, staff training, and service delivery tools. All staff received training in: positive behaviour support, person-centred training, support strategy training, rights training, and customized employment. We changed our hiring process by being more specific as to where we posted our ads and reformulated the questions we ask at interviews to reflect the values, knowledge and skills set that we felt would enhance quality of life of persons served. Staff competencies (an open book quiz on agency culture and procedures) were remade and organized according to the eight QOL domains. Self-advocates have been heavily involved in the restructuring of the hiring process and the trainings that are given to ensure that the transformation was a genuine one.

While we were engaged in this alignment we began re-examining the Personal Goal Planning (PGP) tool we were using, and in trying to align it to QOL realized that we needed something more if we were to truly support the persons served. We researched what would be the best and most efficient framework to implement a successful service delivery plan for the people we serve. The concept of a one-page Individual Support Plan (ISP) was very attractive because it placed great importance on each individual having a copy of the support plan that was meaningful to them, and formatted and written in a way they could understand. It can include pictures (real or clip art) and can be modified in several ways depending on what would be applicable for the person (a video could be made, sign language used, or other creative ideas). It was most comprehensive and inclusive of the individual, supports required, goal planning, and delivery of services.

Although we have always placed great emphasis on knowing the individual, we had not utilized a standardized assessment of the individual's support needs. Through our research we learned about the *Support Intensity Scale (SIS)* (4), which is a unique assessment tool that focuses on: supports needed rather than achievement and increasing personal outcomes instead of behavioural objectives. The conversation that surrounds the SIS is action orientated, which is a principle we highly value. The format we use for the ISP drives the individuals' outcomes and holds our staff accountable to their provision of support. It changes the onus of achievement to support and ensures we give each person what he or she needs to succeed.

Input

In the past, our individual goal planning was in many ways based on assumptions of the abilities that a person did or did not have. Though this approach can seemingly work for a short time, because it comes from a deficit perspective the success is short lived and limited at best. We found this to be problematic for several reasons. This perspective is completion driven and has an emphasis on achievement rather than personal outcomes (i.e. an individual's hopes, dreams, aspirations is an integral part of the process and the focus must always remain on the person served, and the important people in their life). However, a support plan that is solely based on those items, as important as they are, will not be as successful as it can be because it lacks an understanding of the distinction between what is *important to* and what is *important for* an individual, as well as each individual's personal conceptual, social, and practical adaptive skills. Additionally, it does not address the support needs of the individual (1).

Important to includes what a person communicates to others with either their words or their behaviour. *Important for* this includes those things we keep in mind for people with regards to health and safety, as well as what others see as important in being a member of the community (6). This distinction is described more fully in table 1.

A person-centred discussion can easily identify what is *important to* a person and what they would like to accomplish. More difficult to ascertain is what is *important for* a person who is supported. While certain items may be quite prevalent and therefore be easily identified, many *important for's* may go unrecognized without the use of a formal assessment tool. With regards to assets, *social* refers to the abilities a person has socially, *practical* refers to skills used in everyday life and *natural* refers to the supports a person has in their life. A listing of these components to a system of supports is presented in table 2.

Table 1. Aspect of importance to and for the individual

Important To: This includes what a person communicates to others with either their words or their behaviour.

Important For: This includes those things we keep in mind for people with regards to health and safety, as well as what others see as important in being a member of the community.

Important to _______________	Important for _______________

Table 2. Personal assets: An integral component to develop individualized strength-based support strategies

Social (Abilities a person has socially)	
Practical (Skills used in everyday life)	
Natural (The supports a person has in their life)	

The goal planning discussion follows a loose outline (or discovery) during which several broad and specific questions are asked to illicit information, should the individual supported need prompting to discuss and share their goals, aspirations and wants. Goals can be more general or they can be very specific. Whatever the goal is, every single goal can fit into one of the 8 QOL domains. Therefore, after the goals have been decided on they are aligned to the appropriate QOL domain as seen in table 3. In table 3 you will notice that only the goals or *important to* are placed in the chart. The *important for* are recorded later on, in another chart (see table 4). It is important to note that there is no specific number of goals that an individual should have and there is not always a goal in each domain.

Everyone needs support in their life in different measures, in different situations, depending on who they are and what their goal is. Over supporting an individual diminishes the person's gifts and creates an unnecessary dependence, which in turn creates a false sense of safety and security, all the while limiting a person's choices and freedom (3). Not supporting individuals sufficiently diminishes their inherent rights because of the mistaken belief that the person cannot do a particular task (3).

Table 3. Goals and domains

Discussion on Goals: Goals are discussed and formulated conceptually according to the Quality of Life Domains.The domains help guide the discussion.

****Important Note**** There is not always a goal in each domain.

Domains	Goals (based on the things that are important to the person)
Personal Development (education, personal competence, performance)	
Self-Determination (autonomy/personal control, personal goals, choices)	
Interpersonal Relationships (interactions, relationships, supports)	
Social Inclusion (community integration and participation, roles, supports)	
Rights (legal, human-respect, dignity, equality)	
Emotional Well-being (contentment, self-concept, lack of stress)	
Physical Well-being (health and health care, activities of daily living, leisure)	
Material Well-being (financial status, employment, housing)	

The essential factor is to provide the right amount of support, which enables an individual to utilize their personal assets and gifts while striving to reach their goals. With this in mind we use the *Supports Intensity Scale (SIS*) as part of our ISP process to identify items that are *important for* each specific person. It should be mentioned that while formal training to facilitate the SIS is not explicitly required, it significantly raises the awareness of the facilitator and provides clearer more useable information.

Deciding to use the SIS as the primary assessment tool was not a small decision. The SIS is broken down into six categories, a protection and advocacy segment, and a medical and behavioural section. Since considering ourselves a QOL aligned agency, using an assessment that had its own domains was proving to be challenging. Dr. Robert Schalock, had realigned the sections of the SIS to the QOL which allowed us to use the SIS while still maintaining our alignment to the QOL domains. After the initial ISP meeting during which the *important to* is discussed and the SIS completed, the manager reviews the SIS and inputs the information into the aligned ISP framework. The manager, in consultation with the family and key worker, highlights the two most relevant items in each of the domains for the SIS. This is an important step as the development of support strategies and objectives will correspond to these. This is highlighted in table 4. Though the area of support may seemingly not relate to a specific goal of the person, knowing what support they need, will increase our ability to support them as it provides us with an understanding of the “big picture.”

Several people should be present at the initial ISP meeting during which the above mention steps are discussed. Those people are: the individual, family, staff, manager, and SIS facilitator. Items that are incorporated in the first meeting are: the discussion on important to, important for, the discussion on goals, aspirations, and other wants, and facilitation of the SIS. Because the SIS is an all-encompassing tool in that it looks at nearly, if not all, tasks done in an average day, the conversation is extremely rich and often goal planning is fairly accelerated due to this aspect.

Very often persons served as well as their personal networks and direct support staff is very surprised when they realize that they have been over supporting a person in several ways.

Table 4. Most relevant support needs that correlate with the domains

Domain	Assessed support needs (2 in each domain) *Important for*
Personal Development	
Self-Determination	
Interpersonal Relations	
Social Inclusion	
Rights	
Emotional Well-Being	
Physical Well-Being	
Material Well-Being	

The realization of this over support can at first be shocking, followed by being overwhelmed and finally by a feeling of empowerment for the individual and the family. For example: during a SIS it became obvious that Joe was being over supported with regards to doing his laundry, taking public transportation, and cleaning the house. His mother was overwhelmed as she felt she had little time for herself, but at the same time felt obligated to support her son in doing tasks she believed he could not do himself. After the SIS and the implementation of an ISP, Joe now does his own laundry regularly, helps clean the house, and is in the process of learning how to take the bus to his Day Supports. Not only has Joe's individual Quality of Life increased, his Family Quality of Life has increased as well. His mother now has more time and feels less overwhelmed and stressed (7).

Throughput

After the initial meeting and input steps are complete and the most relevant assessed support needs are selected, a brainstorming session is held. The brainstorming is an opportunity to consider what type of strategies might work well in supporting the person served. It is important not to only consider those strategies that have been used so far but any strategies at all that may work well. This is a chance to really consider all possibilities and not restrict your ideas to those that seem immediately feasible. The brainstorm session is a flexible step that can either take place at the initial meeting or afterwards in a team meeting or via phone call. More than one person should be involved in the brainstorming as it is important to consider multiple perspectives and ideas. The brainstorming chart can be seen in table 5.

Table 5. Brainstorm components of a system of supports for the person which may work well

Element ***(this list created by Dr. Schalock)***	**Component / Specific support strategy** ***(these strategies created by the support team)***
Natural Supports	
Cognitive	
Prosthetics	
Skills and Knowledge	
Environmental Accommodation	
Incentives	
Personal Characteristics	
Professional Services	
Positive Behaviour Supports	
Community	

The next step is one of the most important parts of the entire ISP process. This involves connecting a support strategy and support objective to an assessed support need, and applicable goals. Each individual will usually have several support needs (as outlined by the SIS) and the question arises as to how many should be included in the framework. In general, it works well to focus on two support needs for each of the QOL domains; thus detailing a total of 16 support needs in the framework (1). This does not mean that all 16 will be worked on right away. However, the reason for selecting 16 support needs is twofold. One, it means that you are planning not only for what will be worked on now, but for the future as well. Therefore, once a goal or support need is accomplished you can easily move to another one. Second, working through the ISP process for 16 support needs gives you a thorough understanding of the individual and their life; something that could easily be overlooked if only concentrating on the first support need which comes to mind. In selecting a support need it is important to select the two that are most relevant to the person's life. For example, a person may have rated higher (indicating more support is needed) with regards to "interacting with employer supervisors or coaches," and rated lower with regards to "using appropriate social skills." However, if they are not currently working or on a team, it would make more sense to work on the latter support need because improving their social skills would mean the ability to more aptly communicate in their community.

Selecting a support strategy to match a need or goal can be one of the most influential elements of the actual successful implementation of the support plan. Sometimes the support strategies being used end up not being successful. When this happens it means that it is time to reassess and implement different support strategies. The objective has not changed, but the support strategies have. As a general rule, our teams should be ready to use the support strategies for a minimum of three months before any changes or modifications (8). The reason for this is that it is important that we are able to assess whether a strategy is indeed working or not. If a support strategy is only used for a few days it is fairly difficult to determine if the strategy has been unsuccessful and if so why. Often a person needs to become used to a change before the change in support makes a positive difference in the person's life (8). Three months is generally a reasonable amount of time to evaluate this. There can be situations where a strategy is reviewed sooner in specific situations and support staff should always have an ongoing open dialogue with the person served, the individual's personal network, and the staff's direct supervisor. Table 6 shows how an assessed support need is connected to a support strategy and a support objective.

For every support strategy it is important to have a support objective. The support objective should not be a behavioural one, but rather a personal outcome (1). For example, a behavioural objective would read: Joe will not eat too many cookies anymore. A support objective would read: Joe will learn the skills necessary to make healthy decisions regarding snacks. It is important not to select too many support strategies for each assessed need or goal and to consider who will be responsible for the support strategy. Support strategies should be reviewed, and if training is needed it should be provided. It is imperative that each person supporting the individual is fully informed of the support strategies and the support objective so that there is consistency. We recommend daily reporting on the support strategy so that the effectiveness can be gauged and monitored.

The action plan

There are several sections of the ISP and it is important to recognize the differences between the components and the uniqueness of each item. Generally there are three different aspects of an ISP: Staff Support Action Plan, Personal Network Action Plan, and the My Support Plan (1). The Staff Support Action Plan includes several sections: Current Daily Activities and Environments, Interests Preferences and Desired Outcomes, Needed Supports and Goals, Specific Support Strategies, Specific Support Objectives, and Keep in Mind. The Staff Support Action plan is designed to be an easy to read quick guide for the current support strategies currently being used while also giving an overall background about the individual and their life. While two items were selected from each QOL domain in table 6 this does not mean that all assessed needs and goals will be worked on simultaneously. Instead, the most relevant and important needs and goals should be worked on first. How many goals and assessed support needs are worked on will be different for each person and there is no specific number. The Staff Support Action Plan only addresses the strategies currently being used but also has attached to it the final framework so that staff can keep in mind the overall plan.

Table 6. Assessed support needs into support strategies and specific support objectives for the person

An easy way to understand this process is to look at the assessed support need being the "What," the support strategy being the "How," and the specific support objective being the "Why." Ask yourself three questions: What is the support needed for? How is the support going to be delivered? Why is it important that this support is given (i.e. for what purpose)?

(The What)	Support Strategy (The How)	Specific Support Objective (The Why)
Assessed Support Need		
Personal Development		
Self-Determination		
Interpersonal Relations		
Social Inclusion		
Rights		
Emotional Well-being		
Physical Well-being		
Material Well-being		

The Personal Network Action Plan contains the same sections as the Support Staff Action Plan, however there are some points that are different and are important to recognize. Families are complex multifaceted systems that have different needs, expectations, and time availability. While as an agency certain expectations of performance can be mandated from staff, this should not be expected of families. Rather, families should be encouraged to participate as much as they are willing to. Families can provide support in ways that direct support staff cannot. The monitoring of strategies that the personal networks are responsible for should be examined with sensitivity and an understanding that consistency is beyond the agency's control. If a family member or other important member of the personal network would like to monitor the support strategies they provide, this can be very effective, but they should not be pressured into doing so. In working through the ISP it is important to consider how strategies that the personal network has taken on will affect the overall QOL of the person if they are not completed.

Table 7. Support staff action plan

Support Staff Action Plan

Name:
Age:
Date of Birth:
Date:

Current Daily Activities & Environments:

Interests, Preferences, and Desired Outcomes:

Needed Supports & Goals:

Specific Support Strategies:

Specific Support Objectives:

Keep in Mind:

Progress Evaluation Plan

Table 8. Personal network action plan

Personal Network Action Plan

Name:
Age:
Date of Birth:
Date:

Current Daily Activities & Environments:

Interests, Preferences, and Desired Outcomes:

Needed Supports & Goals:

Specific Support Strategies:

Specific Support Objectives:

Keep in Mind:

Progress Evaluation Plan:

Table 9. Supports and Personal Plan

My Support Plan	This is important for my life	These are the supports I need	Is Support given?
Date: **Health & Safety Supports** *I need to avoid potential risks in the community and home* **1)** **2)** **3)** **4)** **5)**	Personal Development – Learning new things Self-Determination – Make my own choices Interpersonal Relations – Family & Friends Social Inclusion – Be part of the community	Personal Development – Learning new things Self-Determination – Make my own choices Interpersonal Relations – Family & Friends Social Inclusion – Be part of the community	**Yes - No** **Yes - No** **Yes - No** **Yes - No** **Yes - No** **Yes - No** **Yes - No** **Yes - No** **Date 1:**
These are my Wishes and Goals **1.** **2.** **3.** **4.** **5.** **Is this improving?** **Yes / No** **Date 1:** **Yes / No** **Date 2:**	Rights – What I am allowed to do Emotional Well-Being – How I feel Physical Well-Being – Being healthy Material Well-Being – Have money and goods	Rights – What I am allowed to do Emotional Well-Being – How I feel Physical Well-Being – Being healthy Material Well-Being – Have money and goods	**Is Support Given?** **Yes - No** **Yes - No** **Yes - No** **Yes - No** **Yes - No** **Yes - No** **Yes - No** **Yes - No** **Date 2:**

The My Support Plan is the plan that the individual keeps on their person. This is an integral part of the overall ISP as it cannot truly be considered a person's plan if they do not retain ownership of it.

The format of the plan uses modified information so that it is understandable to the person. This can include, but is not limited to: words, real pictures, clip art, or PECS (Picture Exchange Communication System). The monitoring of the support strategies with regards to whether the person feels they are being supported is on the "My Support Plan," itself. There is also a section which looks at Health and Safety considerations that are *important for* the person to know. Only the current goals and assessed support needs go on the plan. One important aspect of the individual's plan is that nothing is written on it that the person does not want to be there. For example, there may be a person served who has an assessed behavioural support need. If the person served does not want anything written on his/her plan about a specific behavioural need, then it would not be written there. It would however be addressed in the Staff Support Action Plan and the Personal Network Action Plan (where applicable). A Staff Support Action Plan can be seen in table 7 and a Personal Network Action Plan in table 8. The "My Support Plan," can be viewed in Table 9.

Output

Measuring the impact of the support strategies on the individuals' QOL is the final step (of a continual process) in the ISP. While the reporting/monitoring of the support strategies can be done through a Likert Scale (or similar reporting mechanism) measuring impact on QOL is a much more subjective task. While there are some goals which can be considered complete or 50% attained, measuring impact looks at more than just whether a goal has been finished. Examining impact means reflecting on how the support strategies have influenced the individuals' Quality of Life; often regardless of whether the goal has been accomplished.

This qualitative step involves analyzing data and communicating with the person served (either directly or by proxy), the personal network, and direct support staff. It means noticing small and big trends that have occurred over the three months. As noted above, we have chosen to engage in support strategies for a minimum of three months and look at the impact quarterly. This measurement includes several steps. First the manager and/or key direct support staff speak with the individual (or by proxy) and refer to their one page My Support Plan and review whether they feel they are getting closer to achieving their goals. They also discuss whether they feel that they are being supported in a way that the person served feels is effective.

An individual may not have fully accomplished their goal but their quality of life may have significantly improved. On the other hand, a goal may have been accomplished on the surface, but in-depth analysis could reveal that the individual is unhappy with the final result; thus their quality of life has decreased.

An integral part of the output process is table 10, the ISP Framework for My Support Plan and Support Action Plan. This final table in the framework gives an overview of the individual's assessed support needs, goals, support strategies and support objectives, and considers the impact of the support strategies on the individual's quality of life. A key element of the table is the *important to* and *important* for boxes.

In general, it is been our experience that people want to support people to utilize their skills and increase their independence. In doing so there is great emphasis placed on the *important for* and the assessed support needs (*SIS*). While this is very important it is imperative that the person's goals and aspirations (*important to*) are captured and integrated throughout the plan. The final chart ensures that this aspect is fully accounted for.

When assessing the intended results of the ISP, reflecting on each step of the process can help one recognize what worked, what needs improvement, and what might need to stay the same. It also serves as an accessible clear way for team members and new staff to gain an understanding of the whole person.

Table 10. ISP framework for my support plan and staff action plan

Domain	**Most Important Goals and Support Needs to and for the person** *(important to the person is based on personal goals and expressed support needs; important for the person is based on assessed support needs on the SIS)*	***Support strategies based on a system of supports*** *A system of supports includes:* _*natural supports_ _*cognitive supports_ _*prosthetics_ _*skills and knowledge_ _*environmental accommodation_ _*personal assets_ _*positive behavior supports_ **A specific support strategy needs to be established for each goal and support need**	**Support Objective for each support strategy** A support objective integrates the specific strategy used and the intended result of that strategy. Support objectives are expressed as an action verb such as use, provide, implement, advocate for, develop and access. An example of a support objective would be "provide a behavior support plan to increase incentives" or "to develop online communities to increase social interaction and community participation". **Monitoring of the ISP involves determining the status of each support objective (on a 3-point Likert Scale)**	**Quarterly Review Evaluation: Impact of the Support Strategies on the Individuals Quality of Life** This is an assessment of the intended results. Evaluating the efficacy of the support strategies every three months is an important element of the ISP. While a goal may not have been completely achieved it is important to consider the impact that the support strategies have on the Quality of Life of the person served.
Personal Development				
	Important to:			
	Important for:			
	Important to:			
	Important for:			
Self-Determination				
	Important to:			
	Important for:			
	Important to:			
	Important for:			
Interpersonal Relations				
	Important to:			
	Important for:			
	Important to:			
	Important for:			

Social Inclusion				
	Important to:			
	Important for:			
	Important to:			
	Important for:			
Rights				
	Important to:			
	Important for:			
	Important to:			
	Important for:			
Emotional Well-being				
	Important to			
	Important for:			
	Important to:			
	Important for:			
Physical Well-Being				
	Important to:			
	Important for:			
	Important to:			
	Important for:			
Material Well-Being				
	Important to:			
	Important for:			
	Important to:			
	Important for:			

Culture shift

The culture of our agency plays an extremely important role in the work we do. This is because the belief system which guides our actions is the underlying foundation of our practice. We are firm believers that one has to know "why they do, what they do" (9). Though we have always been an agency which believes in measuring our success in terms of, "are we getting closer or further from our mission statement", there are points of clarity which allow us to facilitate greater alignment to a proactive culture. Realigning our agency to the QOL, and more specifically, the input, throughput, and output, has shifted where we place our emphasis and how we view our role in person centred planning.

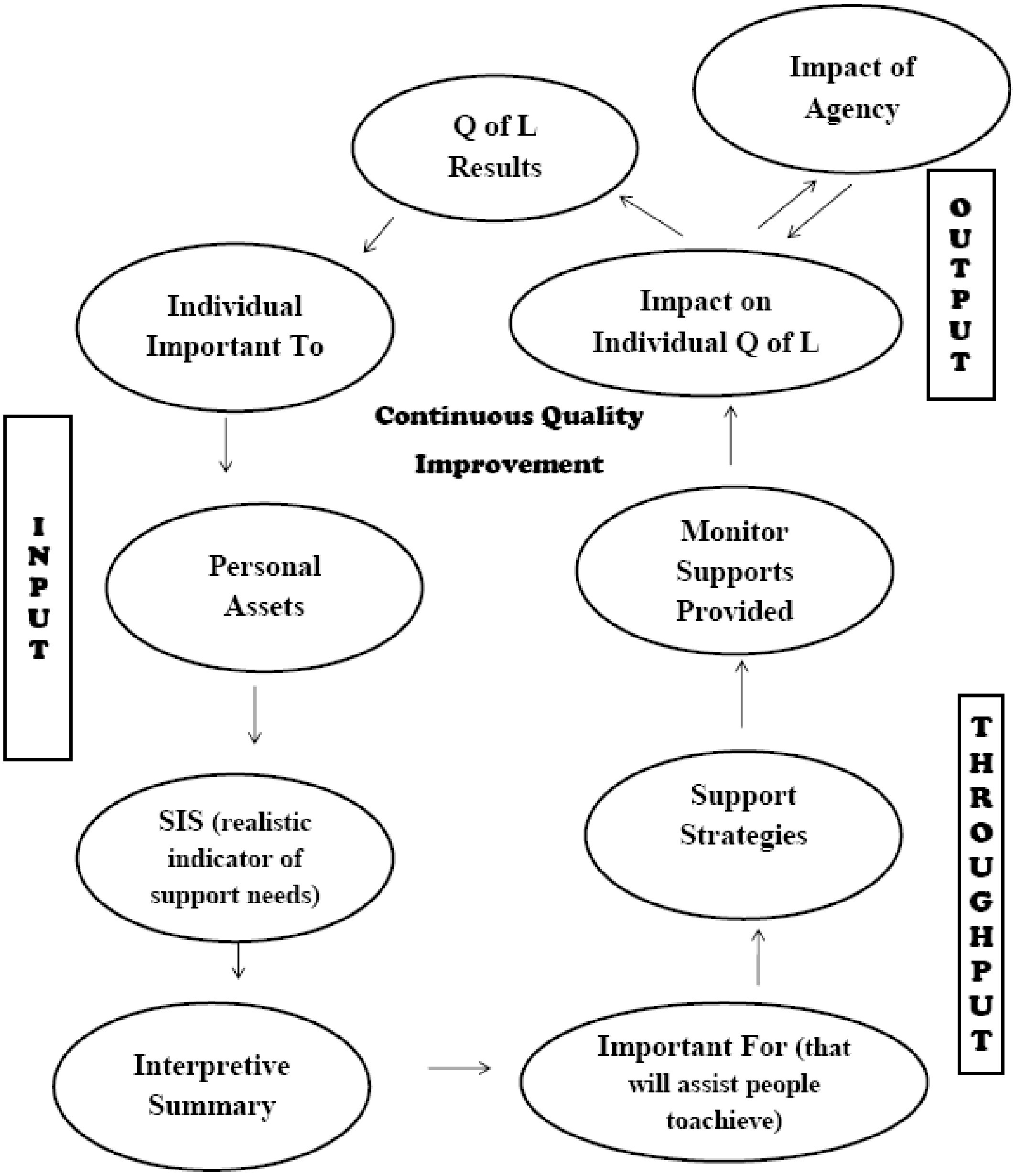

Figure 1. Alignment of agency input, throughput, and output.

Understanding the difference between achievement-based plans as opposed to plans based on personal outcomes has allowed us to focus on what really matters in a person’s life (1). Placing greater emphasis on monitoring supports rather than goal achievement actually propels higher success rates and more importantly greater QOL while focusing on the person’s goals. These simple ideas have transformed our agency from an organization that values person centred engagement to an agency that lives for increasing individual and family QOL. Figure 1 captures the complete alignment of the input, throughput, and output.

Throughout our journey we have learned the importance of celebrating our progress and understanding that mistakes are to be expected. Realigning the agency and our practices has not been an easy task and is one we continue to engage in on a daily basis. We continue to have new trainings, and use creative ways to implement the new support plans and realign the nature of the support we provide.

Conclusion

For our agency, the ISP has proven to be a compass within our day-to-day work. It provides us with concrete direction on a continual basis and emphasizes the importance of person centred support and promotes a commitment to quality support provision. Tools such as the SIS allow us to see both the forest and the trees and reflect not only on *important to* or *important for*, but both. This has been a journey in which we chose to challenge the status quo and evaluate the impact of our current system in order to evolve to a process which truly puts the person first.

We feel that the processes and changes in policies and organization practices described in this chapter are applicable to other organizations and those serving other populations. More specifically, we have found that aligning the input, throughput, and output has been a very significant feature of the ISP transformation. This means that the entire agency, including staff, policies and procedures, outcomes management reporting, dedication to advocacy and support, aligns with each other and the eight QOL domains. This is not a simple alignment, as it requires honest agency and personal self-reflection of an intense nature. Having a reliable evidence based tool is integral as it ensures that the input is personal outcome based without bias. Support strategies that are well thought out, reliable, and relevant formulate an aligned throughput. Finally, sincere focus on the impact of the ISP on the individual’s quality of life aligns the output; which though last sequentially is no less significant.

An important aspect to this organization and others who ‘go down this path’ has been to know that it is acceptable (and even expected) for mistakes to occur, and that the integration of a new system always brings with it new challenges and difficulties to work through. We have had to build new partnerships and connections that could benefit the people we serve, which have enriched our agency and the support we provide. Because the personal outcomes of the persons served are the clearest representative of the performance of our agency, we felt compelled to engage both internally and externally with actionable items to improve the quality of life of the people we support. An agency should feel compelled to monitor the impact of the services that they provide and how that manifests the quality of life of each and every person. We strive to create a culture where everyone is united with the vision of improving personal outcomes as a true measurement of each person’s success.

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Quality of life: Four under-considered intersections

H Rutherford Turnbull III, BA, LLB, LLM[*]
The Beach Center on Disability, University of Kansas,
Lawrence, Kansas, United States of America

Abstract

This paper examines the concept of quality of life and considers its current limitations requiring a broadening of the concept and its application. In doing so the author examines aspects of individual and community living which, it is argued, needs to be further recognized within a quality of life framework. This includes such diverse areas as the role of law and ethics, the nature of personhood and the importance of society in general, as well as the individual's local community, acknowledging and then promoting the status of dignity for everyone regardless of their disabilities. The consequences of such expression are discussed. The interface between such needs along with the broadening of the concepts and principles of quality of life are developed in order to challenge scientists and other professionals to broaden their remit.

Keywords: Quality of life, concept, principles

Introduction

In this paper, I make a modest proposal. It is that those of us involved in the science of quality of life should intersect the science with four under-considered constructs. These are (a) personhood and the social construction of disability; (b) the implications of social constructions for communities and their laws; (c) the consequences of questions that are both self-referential and other-regarding; and (d) compassion, trust, and dignity. As I address each of these, I call attention to some of their policy and legal implications.

I do not intend to describe fully each intersection. Readers presumably already understand the underlying constructs related to quality of life, personhood and social construction of disability, issues of regarded-ness, and compassion, trust, and dignity. Instead, I intend to stimulate a discourse around the proposition that quality of life consists of more than the measurable domains that scientists have

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[*] ***Correspondence***: Professor Rud Turnbull, Distinguished Professor in Special Education and Co-founder/co-director, Beach Center on Disability, 3111 Haworth Hall, University of Kansas, 1200 Sunnyside Drive, Lawrence, KS 66045, United States. E-mail: rud@ku.edu

identified to date. In this respect, I seek to enlarge our understandings about quality of life and to challenge the scientific community to concern itself with some of the law and policy implications of their invaluable science.

I also seek to show that an enlarged understanding about quality of life is entirely consistent. Brown and Faragher (1) invites us to consider how and why many others generalize from the field of intellectual and developmental disabilities. That kind of generalization is explicit in papers Faragher, Broadbent, Brown, and Burgess (2) about education; Wilson (3) about mathematics; McArthur and Faragher (4) about children with disabilities and other challenging circumstances; and Ajuwon and Bieber (5) about blindness.

Ajuwon and Bieber's paper (5) makes the important point that the power of imagination and creativity are elements of quality of life that have yet to be factored into the science of quality of life. Indeed, if I were to rewrite my paper, I most certainly would have included imagination and creativity as domains of quality of life.

Still by way of introduction, one more point is worth making. It is that, indisputably, quality of life science concerns itself with well-being and basic needs and thus with the means for attaining them through policy and practice (6).

Scientists have determined the dimensions of quality of life, as various chapters in this book indicate. And, legal analysts have identified the core concepts of policy – those legal precepts without which policy will not readily advance quality of life. Fortuitously, the combination of quality of life science and policy analysis can provide an evidence-based foundation for still further quality of life research and advancements in policy and practice (7). It is that "next step" with which I am especially concerned here.

To begin the "next step," I propose that four matters deserve our consideration. To put them into a loosely logical order, I begin with the construct called personhood.

The first intersection: Personhood and social construction

The term personhood refers to the how, under national or local norms and law, a person is represented and responded to by others (8,9). It is a bestowed status; it arises in the context of relationships (10); it reflects the degree to which a person has social value (1l); and it changes over time (12).

Congruent with these understandings about personhood, the social construction theory holds that disability is, in large if not entire part, a consequence of how norms, mores, policies, and built environments "cause" an impairment to become a disability (13). Social construction theory is at the root of QOL science. The very life of the person with an impairment is converted to a "disabled" status by how the person is regarded by others. One consequence of this transformation is that the quality of life of a person with a disability is regarded in relationship to the quality of life of those without disabilities and others with disabilities. Not only is disability socially constructed, but so too is the meaning of "quality" of that life.

That is why, in seeking to enhance the domains of an individual's or family's quality of life, QOL science enhances personhood: the more acceptable the QOL-measurable outcomes for the person, the more likely it will be that others will regard the person as worthy; they will confer greater personhood. That was a premise of the right-to-treatment cases (14) that were one ground of the disability-rights revolution that began in the 1970s, even as it is a ground for the Americans with Disabilities Act (ADA) (15) and the Supreme Court's interpretation of ADA in the Olmstead case (16).

One consequence of attempts to reform residential and other living conditions of persons with disabilities has been that the law comes to regard the person as having a right to equal protection under the law and equal opportunities in all of life's domains.

Another consequence, however, may be that the very laws, supports, and services that have allowed a person to have a more acceptable, more normal quality of life may be jeopardized. That is so because the very fact that a person with a disability experiences a certain quality of life may provoke a push-back against the laws, supports, and services that undergird that quality (17). This reaction to progress is grounded none-too silently on a sense that "they have too much and we have too little or should not be burdened any more to pay for all they have."

A still more profound and disturbing consequence may rest on an argument that the entire social construction proposition proceeds from a "bestowed" perspective (18). That is, a person's status is a consequence of what others "bestow" on the person; it is a result of how some regard the person. That bestowal and its consequent status can benefit the person.

But that which is bestowed can be withdrawn (18). Law, community norms, and mores can be reversed. Those who are at one time devalued and then valued can be devalued again. If disability is a consequence solely of social construction, one must be uncomfortable and seek for a far stronger basis for personhood, one that may be grounded in theology or secular ethics. The social-construction approach cries out for a companion, one that rests on a theological or philosophical model of understanding what disability is and why those regarded as having a disability are inherently, not just socially, worthy (18,19).

The second intersection: Ethical communities and the role of law

If we accept the social construction theory, we have to accept the challenge to modify the communities we share with each other, including those with disabilities. That is so because the construction of disability, by definition, derives from community norms and mores. Before I develop that point, I must pay homage to Trevor Parmenter.

Parmenter (20), with his usual and always welcome insights, makes that vital point. From my perspectives as I set them forth here, Parmenter's paper is an indispensable force in expanding our understanding about quality of life. That is so in part because he addresses the matter of ethical communities, which I discuss below. It also is so because he asks us to think about the self-identity of people with disabilities, namely, the self-regardedness that they have and that, as I point out below, we also must have.

I also owe thanks to others. Parementer's point about communities relates not just to those with intellectual and developmental disabilities, but also to others with disabilities and to those who are challenged by debilitating social, economic, educational, and other conditions. Now, let me make my contribution to these matters, with special emphasis on law.

How can communities become more willing and able to be shaped to embrace the personhood – the belongingness – of those with disabilities and their families? To ask this question is to come to yet another intersection, the one where the science of quality of life intersects with law.

One answer to the question about how to modify communities so that they will enhance personhood is to consider the functions that "the law" performs. To state the obvious, law is a technique of behavior modification; it changes our behavior by prohibiting public and private entities from discriminating solely on the basis of disability and by conferring rights and entitlements. More than that, however, law can and usually does effect cultural change.

Indeed, law prompts members of a community to create "an ethical community." In that community, law confers status, what we call equal protection and equal opportunity. In doing that, it enlarges individuals and families' personhood because, in the law's eyes, they are regarded as inherently valuable, not merely legally equal. Thus, the ADA (15) proclaims that disability is a natural consequence of the human condition. That declaration of fact justifies the entire ADA. The logical corollary of the fact (as proclaimed) is that there can be no justification for discrimination based solely on disability. As a matter of law, then, the ADA is justified in insisting on equal protection and equal opportunity.

The community in which equal protection and equal opportunity exist, however imperfectly, arguably is a more ethical community than one in which these bedrock legal principles are unacknowledged or, if acknowledged, are acted on only parsimoniously. In the ethical community, those with disabilities are not merely protected; they are, as well, welcomed. Consider that idea! To say that disability is a welcomed condition may seem radical, but it is simply a way of restating that disability is natural and that a "natural" community that seeks to be an ethical one must therefore welcome people with disabilities. It is regrettable that the ADA does not make this point explicitly, not just implicitly, by inference.

One challenge in fashioning the ethical community is to concern ourselves with the community itself. What is do we mean by “a community”? A community is a site of commonly shared places and spaces. More than that, it is a site in which people with broad common interests have to have some associations with each other; their mere sharing of place and space compels them to have some associations with each other. A genius of law is that it compels members of these communities to confront their similarities and differences and thereby to decide on whom they will bestow personhood and legal standing (21,22). Who, they must ask and answer, is a welcomed member of our community?

Another challenge in fashioning the ethical community is to concern ourselves with our culture. In this respect, we are concerned with not just the law but also our inherited or newly learned mores (23). As powerful as law is in shaping behavior, it is but a regulatory tool. In and of itself, it does not have the power to change our mores. It does, however, have the power to show us what our mores have been, in both their bountiful and denigrating effects, and to offer strategies for preserving the former and jettisoning the latter effects.

The evidence of the law’s power in its intersection with culture lies in the not-so-recent history of changes in law and mores affecting discrimination based on race, sex (the women’s rights movement), gender (the GLBT movement), and, of course, the disability-rights movement.

Law alone does not teach us what our mores have been, are, and might be. The personal experience – the living of history by a single person or family, whether that personal history is grounded on race, sex, gender, or disability – forms each of us and thus all of us. When a critical mass of grievances becomes so large that it compels us, as members of a national, regional, or local community, to act, then the personal and the law conjoin to change culture and thereby create an ethical community.

The third intersection: Self-referentiality and other-regardedness

Another challenge in fashioning quality of life for each other and thereby creating the ethical community is to think about ourselves as members of the community. That self-regardedness asks us to be deeply self-reflective, considering our own quality of life in relationship to community members who have and do not have disabilities. We dare not fail to ask, “Who am I, and who am I in relationship to others?”

By asking that question, we necessarily consider the concept of dignity. Dignity is defined as the state of being worthy, honored, or esteemed (24). It is another way of thinking about one’s own personhood.

For the purposes of self-regardedness, the relevant questions are: “Am I worthy, honored, or esteemed? By whom? Why? What is my personhood? Has it an element of dignity?” For the purposes of other-regardedness, the questions are: “Do others regard me as worthy, honorable, and estimable? Who does? Who does not? Does the law address how others act on their perceptions?” These questions are the ones that the Rehabilitation Act (25) and ADA (15) require us to ask, for both prohibit discrimination based on whether others regard a person as having a disability.

Here, then, is an intersection of law, ethical communities, and dignity. This intersection arises because the core concepts of American disability policy (26) express both constitutional and ethical principles. The constitutional principles are life, liberty, and equality; the ethical principles are family-first, dignity, and community.

Note the last two of the ethical principles. Dignity obtains initially within a family and then within a community – it is a consequence of how family members and then others regard a person. And community entails full participation in communities of one’s choice; choice is an element of dignity (27).

So, just as quality of life research seeks to advance measurable domains that core concepts support (7), that same research implicitly concerns itself with dignity. That is so because dignity is a consequence of embedding the core concepts into our laws and thus into our culture and communities.

Embedding dignity and core concepts can be tantamount to creating ethical communities.

For the purposes of our being in an ethical community with those affected by disability, the questions are: "Are they worthy, honored, or esteemed? Do I regard them that way? Do I confer on them the same dignity that I believe I myself have, whether or not I have a disability or other distinguishing trait?"

A person's dignity is a consequence of how not only how others regard but also, and more significantly, how they respond to the person. This being so, the more compassionate the response, the higher the individual's dignity and the greater individual's the personhood.

At this point in my essay I must invoke the memory of the person who was the most prominent focal point of my work and of the QOL research that my wife Ann has carried out. That person is our son Jay. The memory has many lessons, none more relevant to this essay than this:

> No single indicator of quality of life, nor all of them together, is inherently meritorious unless, when it is attained, it contributes to the worthiness – the dignity and personhood – of the person and family.

When Jay, who had intellectual disability, autism, and a rapid-cycling emotional and psychological disorder, was only seven years old, I argued that less able does not mean less worthy (28). Even though that assertion did not explicitly refer to his dignity, it did invoke it, for dignity, by definition, entails a sense of worthiness, of esteem (24). After Jay died 33 years later, Wehmeyer (29) said that Jay taught us professionals that we are not merely in a discipline-grounded profession; instead, we are in the "dignity business." I concurred: dignity was an essential element of Jay's quality of life (30), even as it was an indispensable principle of ethics arising from law (19). That is what I know.

What I do not know is the answer to these questions: Do QOL scientists explicitly acknowledge that dignity is an essential element of QOL? Or do they use proxies for dignity? If so, how do they measure dignity? If they do not, what is missing?

In asking these questions, I do not at all disparage quality of life science. Indeed, one of the consequences of that science, as I am arguing here, is that it motivates us to consider inextricably related issues.

The more the science requires us to attend to policy and practice, the more it can raise the quality of life of persons with disabilities and their families. As their QOL rises, they may experience greater personhood and dignity, both as they experience them (the subjective experience) and as others perceive the person (the objective experience). That is so because they may be regarded by others as more like than unlike those who bestow personhood.

I say "may" because it is not certain that a raised quality of life necessarily enhances personhood and dignity. At the micro-level, those in close contact with a person/family affected by disability may sense a worthiness in the person/family; this sense of worth dignifies. Yet that microcosm of an "ethical community" – that tiny community surrounding the person and family – may not universally obtain at the macro or meso levels.

Who does not know a person with a disability and the person's family who has a dignified life? And who, at the same time, believes that all persons and families have a dignified life? The likely answer to the first question is that nearly all of us in the field of intellectual and developmental disabilities can identify one or more dignified persons and families affected by a disability. The equally likely answer to the second is that none of us can yet affirm that dignity approaches a universal condition for those affected by disabilities.

I have argued in this chapter that the more quality of life science requires us to attend to policy and practice, the more it can – repeat: can – elevate the personhood and dignity of those affected by disability. It can do so by making clear that policy and practice make a positive difference. When policy favors supports and services and when law authorizes the supports and services and appropriates funds for them, benefit obtains: QOL improves, personhood is likely to be acknowledged, and dignity is apt to rise. That is one scenario. It is not, however, the only or an inevitable one, as I also have argued earlier in this chapter. That argument is worth a few more words.

Indeed, the higher the QOL of a person or family, the lower their claim to supports and services might be. I say "might" because there may be a tendency to withdraw supports and services on the spurious ground that "well enough" has been obtained: "Well, enough of those supports and services. After all, look at how well the person and family are doing, how full of quality their lives are."

That reaction invites, it even demands, the reduction of the very services and supports that have contributed to the life (lives) that can be characterized as having "quality"; these are the enviable lives, those nearly all of us would want to live if we did not know what kind of life we would live if chance were the only factor that shapes our lives. It is not that the person or family do not need the supports and services; they do. It is, rather, that they are at risk for losing them simply because they have attained what some may regard as a too-well lived life.

This reaction threatens individuals and families affected by disability. It also threatens persons and families who face other challenges, such as those that other authors in this book describe. Here, again, disability quality of life consists of promises and threats that generalize outside of the field of intellectual and developmental disabilities.

As the science of quality of life describes and measures quality, quality can be a two-edged sword. That is not an argument against the science. It is a caution about the forensic uses of the science. And that caution returns me to the questions about dignity, because I am arguing that what science now measures may be too little: dignity is a component of quality of life.

Is dignity measured by proxies, or is it not measured at all? Should it not it be an explicit consequence of the science?

To consider these questions, it seems useful to return to the concept of personhood and the desideratum of dignity-conferring communities. In returning, we travel a path laid by the discipline of positive psychology, meet the concepts compassion and trust, and consider their relationship to dignity.

The fourth intersection: Compassion, trust and dignity

Positive psychology concerns itself with empathy (31). It seems to me that individual and family QOL depend not just on measurable outcomes related to QOL domains, but also on the empathy that flows from one person to another and the compassion that empathy can stimulate. Why?

It is because empathy is the state of being aware of and vicariously experiencing the feelings, thoughts, and experiences of another (24). It is manifest in what I long ago called the "shoes" test: We who study, render care to, and advocate for those with disabilities must step outside of ourselves and take the place of those we serve, lest we fail in our legal and ethical duties of care to, for, and with them (32,33). Empathy allows us to see others as they might see themselves. By definition, it is an act of identification, nothing more; it is an inert status; it does not necessarily prompt action.

But empathy has the potential for action. When we imagine ourselves as "the other" person, we may be spurred to act. If we respond to that stimulus, we demonstrate compassion. Why? Because compassion involves consciousness of others' distress and – repeat: and – a desire to alleviate the distress (31,34). Desire is the spur to action. Not just any action, but principled action.

In taking into account the idea of principled action, we come to yet another intersection. It is the one where QOL science meets theories of justice. That is a discourse far too lengthy for this chapter. Suffice it to say that the core concepts of disability policy in the United States (26), and indeed in the United Nations Convention on the Rights of People with Disabilities (27,34-36) proceed on the theory that there is a natural law right to dignity that each nation's laws can advance.

With respect to that assertion, I must repeat my argument from 2001 that the ethical principles that overarch the core concepts include family as the fundamental unit of society, dignity, and community (19). Family is the core unit of society and often the first conferrer of dignity; dignity is the outcome of action by family and community/society, and community/ society is the context for family and dignity even as community is the context for personhood and dignity.

Let me try to alchemize these abstractions. More than a decade ago I gave a keynote address to the AAIDD's annual meeting and spoke about "mutuality of need and reciprocity of vulnerability" (37). My argument was that we need each other. I should have said more. I should have said at least this: Mutuality evokes empathy and compassion.

Indeed, I should not have stopped there. I should have asserted that trust is indispensable to the ethical community. Trust is the assured reliance on the character, ability, strength, or truth of someone or something (24). It is what combines with compassion when theories and law do not resolve the damnable decisions we must make. No more acute evidence of that statement occurs than when the "edges of life" are sharp, when a new-born comes to this world with massive anomalies or a person who has lived longer is on the threshold of death.

When a person with a disability is at the edges of life, law and principles may guide us. Compassion and trust, however, are the ephemera that will teach us what to do when theories of justice, principles of law, and laws themselves do not accommodate our desire to be compassionate and thereby ensure a quality of life and of death (38). Nor do "shoes" tests and their implicit components of empathy and compassion guard against decisions that a certain life, at its edges, is not to be continued but is to be allowed to expire, albeit palliatively (39).

That is not to say that theories of justice are inapposite. Quite the contrary is true. Justice is an ingredient of the diet that the science of quality of life should feed upon. But justice does not answer all questions, and law does not guide all action (37).

I cannot recount for others, only myself and Jay's mother Ann how abstractions become concrete. I can, however, try to give more than a dash of reality to the abstract, relying on anecdote from our family (Ann, Jay's sisters Amy and Kate, and myself).

While Jay lived, was our motivation toward Jay's and our own "well-being" and "quality of life"? Yes. Absolutely. But there was more: there was the moral imperative toward his dignity, an imperative that arose from Jay's and our family's "mutuality of need and reciprocity of vulnerability" (37).

Undoubtedly, Jay was the primary agent of his quality of life, the principal originator of his dignity (38). We were merely his agents; his multiple and significant disabilities required surrogates.

More than that, unless he could attain a quality of life, we too would find quality elusive in our lives. We five people – Jay, Ann, Amy, Kate, and Rud – were like a mobile: any slight breeze, much less the most powerful that moved one of us, moved all of us (40). Thus, mutuality and reciprocity and, because of them, empathy and compassion were the necessities for each and all of us in QOL terms.

Empathy and compassion were necessary during Jay's life; combined with desperation, determination, vision, skills, and resources, they were the ingredients of his dignified life. By themselves, however, they were insufficient when we confronted Jay's death, when the existential demanded action.

As he lay on the floor of his home, cyanotic, monstrously intubated, injected with drip lines, shocked with paddles, and totally unresponsive, Ann and I declared, "It is over. Stop. Jay would not want to live other than as he lived, and we cannot bear for him not to be the person he was" (30). In that one statement, we compressed two perspectives on quality of life – his and ours.

To this day, some four and one-half years later, we believe we acted compassionately, both for him and for ourselves and Amy and Kate. Did we face a conflict of interest: his life balanced against our caretaking responsibilities? Of course. Indeed, we argued that case about conflict to ourselves, challenging ourselves about the decision we would make.

Within its four corners, however, the question still remains: Did we act compassionately for Jay? We think so: Jay would not have wanted to exist other than as he had been all his life.

What justified us in saying "Stop"? It was the simple fact that we had earned his trust through decades of care of and for him. Throughout his life, he trusted us to decide for him when he could not. In extremis, who would be justified in countermanding our decision? Theories justified the law and quality of life informed our decision. But compassion and trust played their indispensable roles.

Conclusion: Doing science more broadly

It is now timely to return to the beginning of this essay. I know many of the quality of life scientists. I know that they are deeply sensitive to matters of personhood, social construction of disability, self-referentiality and other-regardedness, and compassion, trust and dignity.

But I do wonder whether the science's quality of life domains do full justice to what quality of life is -- to the fact that there is more, much more, to quality of life than is contained in the domains that the science has identified.

There are risks in measuring only the quantifiable, in measuring only the domains now identified. I have identified some of those risks above.

There is another risk. It is the risk that what we define and value now as quality of life may later become perverted and thus lost. Allow me to argue the point historically and then connect my argument to this essay.

Deinstitutionalization led to community-based group facilities that, now, seem as objectionable on some grounds as institutionalization did several decade ago. Thus, we are now in the business of de-facilitation: abandoning the congregate facilities that we created in order to deinstitutionalize.

It may be that an antidote to a potential perversion of the science of quality of life, its constructs and domains, and their utility for progressive law and policy is to acknowledge that, however important the constructs and domains are, quality of life does not obtain without our careful attention to the source and nature of personhood; without our engagement with issues around the social construction of dignity; without our actionable concern for self and others; and without our careful attention to the routes that compassion, trust, and dignity can lead us to follow.

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Inclusion and quality of life: Are we there yet?

Trevor R Parmenter, AM, BA, PhD[*]
Centre for Disability Studies, University of Sydney, Camperdown and School of Rural Medicine, University of New England, Armidale, New South Wales, Australia

Abstract

This paper discusses various barriers people with intellectual and developmental disabilities are facing in achieving social inclusion and a good quality of life. It is proposed that a key aspect for a person to perceive their having a good life quality is their self-identity or self-image. It is argued that there is a critical link between the concepts of quality of life and genuine community inclusion for people with intellectual disability. Inclusion and quality of life are examined within the context of philosophical, economic and political forces. The building of social capital, community capacity and the development of interdependence as an antidote to rampant individualism will be explored. The development of an ethical community could provide a framework in which to meet the broader societal challenges that not only face disadvantaged groups, but the community generally.

Keywords: Quality of life, inclusion, intellectual disability

No man is an island, entire of itself;
Every man is a piece of the continent,
A part of the main.

John Donne, Meditation XV11

Introduction

Quality of life has become a ubiquitous phenomenon in the field of intellectual and developmental disabilities (hereafter intellectual disabilities) since the groundbreaking work of scholars such as Roy Brown, David Goode and Bob Schalock who first wrote on the concept in the late 1980s. It is extremely useful to understand the history of the concept, which probably had its origins in the Aristotelian expression eudaimonia that Aristotle referred to as an objective degree of satisfaction of your needs and living a life of virtue. Early Greek philosophers rigorously debated the relative merits of objective and subjective

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[*] ***Correspondence***: Professor Emeritus Trevor R Parmenter, AM, PhD, Centre for Disability Studies, Medical Foundation Building, University of Sydney K 25, Level 1, 92-94 Parramatta Rd, Camperdown, 2050 Australia. E-mail: trevor.parmenter@sydney.edu.au

aspects of the good life. In more modern times, Thorndike (1) was one of the first scientists to study the quality of life on American cities in the 1930s, specifically in terms of objective characteristics. However, most contemporary writers agree quality of life consists of both objective and subjective dimensions. The concept of "well-being" is suggested by some as a preferred concept to "quality of life" (2).

Various approaches to the concept, including the measurement of health outcomes, have been adopted in the health field; including intensive work by the World Health Organization (3). To some extent, researchers in the field of intellectual and developmental disabilities have not entered into the broader debates on the usefulness of the phenomenon (4,5).

Again, we need to embrace wider world contexts in our debates concerning issues which appear highly pertinent to our field of inquiry. It is suggested that we need to explore concepts in our field through the prism of the broader historical, philosophical, moral, economic, social and political contexts within which all people exist. We are in danger at times of being too introspective in our consideration of research, policy and service issues relating to people with disabilities. Hence, this paper explores issues related to social inclusion and quality of life for people with intellectual disabilities in the context of forces in the wider community. Without this broader perspective I am afraid these concepts run the danger of becoming mere rhetoric, largely ignored outside of the disability environment.

Self-image and quality of life

I recount a worrying phenomenon in the context of the London Paralympic Games held in 2012. There were glowing reports in the world media on the remarkable achievements of athletes with disabilities and corporate sponsors were anxious to bask in the glow of those achievements. However, when questioned as to whether they would invite these athletes to become involved in sponsoring their products, as is the case with famous sportspeople without disabilities, there was an ominous silence. Apparently, they were not prepared to risk the possibility of the negative attitudes the general population still holds towards people with disabilities affecting their product image.

It is the image people with intellectual disabilities may have of themselves, however, that I want to address. My proposition is that without a sound image of themselves, this population would find it difficult to experience the feelings of well-being or quality of life. Despite having suggested that we need to address issues in the disability field in wider contexts, there is a case for analyzing the concept of quality of life through the lens of the epistemology of disability (6); in particular from a symbolic-interactionist viewpoint (symbolic interactionism, a sociological theory, that suggests the way we learn to interpret and give meaning to the world is through our interactions with others).

The negative stereotypes and attitudes toward people with intellectual disabilities are pervasive (7,8) and impact upon the development of their self-image. In his discussion of the phenomenon of labeling, Burbach (9) suggested that people with a disability are in a double-bind situation. In coming to terms with what it meant to be disabled, they are confronted by two, at times conflicting, messages. One comes from outside and is influenced by the social order. The other comes from within and relates to what they know they can or cannot do. So, on the one hand they have to come to grips with the negative aspects of their personal condition, and on the other, cope with the negative effects of stigmatization and stereotyping. I have earlier suggested (10) that, "from a philosophical position there is a conflict between the existential nature of the person and the social nature of human experiences" (p. 267).

One of the factors that impacts upon both the internal and external image-influencing process is the traditional assessment and classification system that surrounds the diagnosis of intellectual disabilities. The person is continually assessed on their perceived deficits and weaknesses, rather than upon what they can do. The move to a classification system which looks at the competencies, needs and plans a person with intellectual disabilities has, and the supports s/he may need to perform them, has been a welcome initiative (11). Elisabeth Dykens' (12) call for an emphasis upon positive psychology in the context of intellectual disabilities is apposite:

> "While mental retardation (sic) is indeed defined by negatives, and the field caught up with the external, I propose a future research and practice agenda based on *positive internal* states, including happiness, contentment, hope, engagement, and strengths. In making these conceptual shifts, I turn to recent breakthroughs in mainstream psychology, and show how aspects of positive psychology apply to those with mental retardation (sic). … Positive psychology benefits those with mental retardation (sic) and this population can uniquely inform positive psychology" (p.185)

The "capabilities" approach of Amartya Sen (13) and Martha Nussbaum (14) also focuses on positives rather than negatives. For instance, Nussbaum has proposed ten central human capabilities, which are embedded in a social justice framework and resonate with many of the theories of quality of life. Nussbaum's central human capabilities are: Life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; contact with other species (e.g. pets); play; and control over one's environment. Dixon and Nussbaum (15) commented that, "Nussbaum has argued that, as bearers of equal human dignity, adults with cognitive disabilities are entitled to all the capabilities on the list, up to the threshold level set for all (p. 549)". This approach is also an antidote to utilitarianism, which will be addressed later.

People with intellectual disabilities are faced with conflicting messages when trying to establish a coherent meaning for life, as well as creating and maintaining self-esteem. They can either exist in an isolated and over-protective environment which leads to socially un-validated meanings, or they can conform to the patterns of behavior expected of them by society generally. Neither of these approaches leads to a satisfactory resolution to the question of how these people define their own meanings. This brings us to the nub of the quality of life issue. In this context I have suggested that, "quality of life represents the degree to which individuals have met their needs to create their own meanings, so they can establish and sustain a viable self in the social world" (10, p.267). The principles of symbolic interactionism suggest that there is a need for co-sensuality whereby humans help each other unfold and establish contact and unity in their social existence.

It is interesting that the special education curriculum for students with intellectual disabilities used to place strong emphasis upon the notion of "social competence" (16). Early research into the preparation for employment for this population also emphasized the importance of building of social skills and relationships (17,18). The building of social relationships for people with intellectual disabilities provides a mechanism for reciprocity and the development of a positive self-image.

Within a symbolic-interactionist/ecological theoretical perspective I developed a quality of life model (10) which included three interactive components: the person's conceptualization of self; the person's functional behaviors within the environment; and societal responses the settings might make to the individual. The *self* component included both cognitive and affective domains; the *functional* included areas such as social interactions, occupational/material wellbeing and community living; and *societal responses* included attitudes, value systems, economic and political circumstances and access to support services. It is proposed that the strength of the model lies in its emphasis upon how well the person with an intellectual disability perceives him/her self within a community. What is paramount is the level to which the person grows and develops as an autonomous individual within an interdependent societal context, with an opportunity to achieve his/her hopes and aspirations, a key feature of the contemporary person-centered approach to life long planning (19).

This argument would also resonate with the challenges families with a child with a disability may face. In many cases, parents and siblings tend to isolate themselves from friends and the wider community, fearing stigmatization and rejection. In one of my research studies the father of twins, both with disabilities, purposefully committed an offence which led to a jail term, because he was unable to cope with the pressures of having two children with disabilities. This is not an isolated case of family breakdown as a result of the psychological pressures brought about by the birth of a child with a severe disability.

As principal of a special school for students with intellectual disabilities one of my tasks was to assist them to develop resilience to counter the stigmatization they received from students from mainstream schools who used the same public transport. In fact, one of the major reasons for their enrolment was that the regular school system had rejected them. My staff and I worked with the families who experienced a similar degree of rejection, to help them build pride in their children's talents rather than concentrating solely upon their weaknesses.

On another positive note, research has demonstrated that families, and mothers in particular, valued the opportunities that early intervention programs and playgroups afforded them to develop friendships with other families with or without children with disabilities (20,21).

Moral status of people with intellectual disabilities

Historically, society's continued denial of the humanity of a person with intellectual disabilities, as well as it seeing such persons as a disposable commodity, challenges us. The question of the personhood of people with intellectual disability has been an issue since antiquity; from Plato and Aristotle through to Luther and Locke. Each of these writers proposed that an intact intellect was the *sine qua non* for humanness. For Plato, low intelligence was something to do with the nature of slave mentality (22). Aristotle (23) maintained that:

> "…the deliberative faculty is not present at all in a slave; in a female it is present but ineffectual, in a child present but underdeveloped"

Martin Luther saw demonic forces underlying mental disorders:

> "Idiots are men in whom devils have established themselves, and all the physicians who heal these infirmities as though they proceeded from natural causes are ignorant blockheads, who know nothing about the power of the demon" (24)

Despite ushering in the "Age of Enlightenment", John Locke (1623-1704) maintained that the defining characteristics of personhood were rationality and consciousness, including self-consciousness. Locke's writings reflected the widely held view that persons with intellectual disabilities do not attain the same level of personhood as those of higher intellect. He drew a comparison between animal and "idiot" intellect (25).

In more modern times, the concept of *otherness* of persons with intellectual disabilities was developed by people such as the epidemiologist Dr FG Crookshank, who in 1924 asserted that Down syndrome represented a regression to non-human species (22). Likewise in 1968, Boyd and Fletcher [cited in Parmenter (26)] proposed that someone with a disability such as Down syndrome is not even a person. Goodey (22) in this context commented,

> "It would hardly be surprising, given how all the historical evidence shows that the psychological characteristics of modern intellectual disability are a distillation of former social, racial and class stereotypes". (p. 245)

In answering the question as to what lies at the heart of this *otherness* and its consistent and potent source of oppression for this population, Stainton (21) suggested that, " …intellectual disability strikes at the very heart of classical and modern ideas of value and humanness" (p. 115). Clapton (27) argued that, "…Judeo-Christian beliefs and practices have intersected with philosophical notions of the superiority of the mind, the orthodoxy of reason, the primacy of rationality, and the control of the body" (p.36). In 1985 the Australian bioethicists Helga Kuhse and Peter Singer (28) wrote:

> "Decisions about severely handicapped infants should not be based on the idea that all human life is of equal value, nor any other version of the principle of the sanctity of human life. … There is, therefore, no obligation to do everything possible to keep (them) alive in all circumstances. Instead, decisions to keep them alive - or not to do so - should take into account the interests of the infant, the family, the next child, and the community as a whole". (p.172)

More recently Singer (29), suggested:

> "To have a child with Down syndrome is to have a very different experience from having a normal child. It

> can still be a warm and loving experience, but we must have lowered expectations of our child's ability. We cannot expect a child with Down syndrome to play the guitar, to develop an appreciation of science fiction, to learn a foreign language, to chat with us about the latest Woody Allen movie, or to be a respectable athlete, basketballer or tennis player". (p.213)

It is illuminating that research portrays a dramatically alternative view of the capabilities of people with Down syndrome and people with intellectual disabilities more generally.

Commentators, including Carlson (30), Kittay, (31), Nussbaum (14), Reinders (32), and Sen (13), have questioned the utilitarian bioethics approach to the issue of the personhood and the moral status of people with intellectual disabilities. They have essentially asserted that all human beings have the same moral status, irrespective of their cognitive capacity. On the other hand, bioethicists such as Singer (33) and McMahan (34), who ascribe to the utilitarian reductionist approach to ethics, based on the principle of the greatest good for the majority, argue that moral status does depend upon some aspects of cognitive ability, a view that can be applied to humans and nonhumans. Their position is that as some animals have a higher cognitive capacity than people with severe or profound intellectual disabilities, it should follow that animals can be elevated to the moral status of humans.

Philosopher and mother of a daughter with severe intellectual disability, Eva Kittay (31), suggested that philosophers need(ed) to uphold two fundamental ethical precepts in their philosophizing. This injunction is extremely apposite in the context of the utilitarian view. The first is *epistemic responsibility*, which means knowing the subject that you are using to make a philosophical point; and the second is *epistemic modesty* which means knowing what you do not know. Kittay has argued that writers such as Singer and McMahan simply do not have sufficient personal experiences of living with and knowing people with severe intellectual disability, hence her emphasis upon the two ethical principles. To support her argument, Kittay related her witnessing a resident with a severe to profound intellectual disability living in a group home with her daughter, mourning the death of his father. Here her argument was that this is evidence of the humanity of this person. Singer and McMahan, however, might respond that elephants also demonstrate the capacity to mourn the death of one of their herd.

It is interesting that as Singer over the years has come to recognize the capacities of people in the mild to moderate range of intellectual disabilities (for example those with Down syndrome); his case now rests more on those with severe to profound levels of intellectual disabilities (31).

There are those, however, who question whether reliance upon the moral status of people with intellectual disabilities provides sufficient protection from harm. In his philosophical reflection on the notion of moral status, Silvers (35) has argued that,

> "Appeals to moral status do not settle debates about whether there are obligations to provide protection and support for individuals with disabilities, because the idea of moral status is as contentious as the disagreements it is invoked to resolve". (p.1014)

Silver proffered an alternative approach, guided by the values and procedures contained in inclusive theories of justice.

In his book, *The future of the disabled in liberal society: An ethical analysis*, Reinders (32) suggested an approach beyond what he termed "the narrow conception of morality". In essence, Reinders argued that each of us has a moral responsibility for dependent people that has a different basis than a conception of the person in the liberal sense. For instance, he suggested that:

> "…dependent others are accepted because their lives are placed in our hands. We can reject their existence and consider their lives are not worth living. We can leave them to be taken care of by their families and grant them the right to be sovereign of their own lives. But we can also accept responsibility for the fact they are part of the web of social relationships that constitute our moral world". (p. 153)

I find Reinders' approach to the moral status of people with intellectual disabilities compelling, for it brings us back to the identity issue - not so much the identity of the person with the disability, but to our own moral identity in relationship to how we react and respond to them - giving, but not necessarily expecting anything in return. Reinders' position is also very pertinent to the nature of family quality of life in the context of having a child with a disability.

The notion of inclusion

In her *A transformatory ethic of inclusion*, Jane Clapton's (27) concept of a "metaphorical quilt" provides a useful framework within which to examine various perspectives of inclusion/exclusion. Her "quilt" provides a meta-discourse on the meaning of disability; four pieces of which are: profound exclusion, technical inclusion, legislative inclusion and ethical inclusion.

- **Profound exclusion** describes a view that embraces the undesirability of people with intellectual disability and their being a threat to society. The intention is to exclude them from society in institutional settings. Intellectual disability is perceived as a tragedy and associated with burden and uselessness. Thus, debates about sterilization and eugenics, prevalent in the institutional era, consider that the sacrifice of people with disabilities is for the greater good.
- **Technical inclusion** focuses on needs and the provision of supports in the least restrictive alternative in the community. Philosophies of Normalization and Social Role Valorization are embedded in this perspective (36). The focus is on technologies to facilitate community living, based upon a negative deficits-based ideology. This perspective results in human service workers being needed in all facets of the lives of people with lifelong disabilities. The underlying theme is that their care needs to be "managed" by bureaucratic, administrative and professional procedures, including professional assessment processes to determine eligibility for care and support. While people with intellectual disabilities may be physically present in the community, they remain socially segregated. In other words they are IN, but not OF a community.
- **Legislative inclusion** adopts the discourse of human rights and citizenship. Independence and autonomy are prized over dependence; and support over care. This is a movement to address social oppression and instill socio-political change. Claiming to have the same rights as others, people with intellectual disabilities find themselves in the paradoxical situation of seeking equality by highlighting difference. Legislative inclusion assumes moral agency, rationality and autonomy; whereas people with intellectual disability may require or prefer inter-dependent relationships. Because of this, people with intellectual disabilities are potentially disqualified from legislative inclusion. The emphasis here is on the *public* domain.
- **Ethical inclusion** refers to an ideal. It is readily observed in the *private* arena of relationships of acceptance. The emphasis here is not on independence, but inter-dependence, mutuality, flexibility and possibly chaos as diversity and complexity are privileged over "normal". This view accommodates difference and redefines moral personhood.

The deinstitutionalization movement which commenced in the late 1960s in Scandinavia was a reaction to the wrongs of the period of profound exclusion which not only enveloped those with intellectual disabilities, but also many others on the margins of society. The simplistic response to institutional living was to relocate former residents into small group homes in regular community residential settings in the belief that physical presence alone would lead to community acceptance and inclusion.

Research has shown that in many cases the characteristics of institutional living remain, irrespective of the size of the residence (37). For instance, basic choices, such as with whom the residents would like to live, were in most cases arbitrarily ignored, and the situation today has not much changed in this respect.

Technical inclusion

The move to what Clapton described as "technical inclusion" was based on the political realities at the time, that paid "care" was still required, but little thought was given to the underlying rationale as to why these people were segregated in the first place. The prevailing philosophy at the time was the need for training to promote "independence". This stemmed in part from researchers, whilst working in the institutional settings, who were able to demonstrate the learning potential of this population (38,39). Their research findings and subsequent advocacy contributed significantly to the groundswell of agitation which led to the closure of the large segregated settings. The logical positivist movement, based on the early work of psychologists Watson and Skinner, certainly made significant contributions to improving the functional behaviors of people with intellectual disability (40), but little attention was given to the development of relationship skills and friendship network building.

Schwartz (41) has provided an eloquent description of the concept of "technical inclusion" which illustrates the underlying neo-liberal/classical approach most western countries have embraced in providing human services to disadvantaged populations. He described this as the "professional/ bureaucratic" paradigm, which suggests that human needs can be met through structures and methods that are no different from those used to build automobiles or to run a ship. Providing there is sufficient technology and adequate human resources available, this approach assumes that most personal and social problems are able to be "fixed".

Cocks and Cockram (42) argued that formal human services now represent powerful social institutions whose power,

> "…has been enhanced through the adoption of bureaucratic professional and technological means, and a union with judicial sources of legitimacy. These purposes are a far cry from a conception of human services looking after the wellbeing of vulnerable people and facilitating their empowerment and self-determination". (p. 224)

Mansell and Ericsson (43) in their comparative review of "community living" practices across the United Kingdom, the United States and Scandinavia, suggested that despite commitments to deinstitutionalization, the spirit of that era remained pervasive, because the beliefs that led to segregation live on in public policy; in the ways support services are provided and in the denial of citizenship for people with intellectual disabilities.

A more recent review of the empirical literature on the level of active participation of people with intellectual disabilities in the community (44) revealed some disturbing results:

- The average number of persons in their social network was 3.1; one of which was a paid support worker;
- They are 3-4 times less employed than non-disabled peers;
- They were less likely to be employed competitively and were more likely to work in sheltered workshops or segregated settings than those with other disabilities;
- They were less likely to be involved in community groups;
- Leisure activities were mostly solitary and passive in nature; and
- They were generally accompanied to an activity by support staff.

The review concluded that people with intellectual disability living in the community certainly participated more than those living in segregated settings, but their level of participation was still much lower than non-disabled people and other disability groups.

Inclusion is not a static concept, but a process most of us work on throughout our life span. Clapton (27) commented that "…inclusion as a concept, implies a process of transition and transformation – a process of spatial movement and change" (p.23). In the field of disability the concept has been seen as an antonym to segregation, but have we sufficiently addressed the underlying factors that have led to the removal of people from the general society deemed to be a threat to the common good or a threat to themselves?

Attitude studies concerning people with intellectual disabilities have indicated that the closer the respondents are to the person's life, the more positive are the attitudes. On the negative side there remain vestiges of the eugenics approach on the part of those who are more distant from shared personal experiences (7). It would seem we have based emerging policies as a reaction to past practices such as institutionalization, rather than taking a more proactive approach which asks the question "what type of life would I want to live if I had a disability?" The obvious answer would be a range of responses little different from those of people in the general population.

It is the lived experiences of people with intellectual disabilities, however, which is the true test of their acceptance as an integral part of the community. It would appear that this acceptance and the opportunity to forge meaningful relationships with friends of their choosing is an essential contributor to their sense of well-being and a life of quality. Inclusion implies a sense of reciprocity and interdependence, rather than simply a physical community presence, which appears at times to be an index of inclusion in public data banks (45).

The rights approach

Clapton's third piece of the quilt concerns the discourse on human rights and citizenship. Inclusion of people with disability in general society is a benchmark of the United Nations *Convention on the rights of persons with a disability* (46) and represents the "Rights Approach" to the support of this population. While countries may sign and ratify such conventions, it is argued that this is a necessary, but not sufficient mechanism to ensure that the rights are exercised in practice. Owing to the nature of the United Nations' structures, it is national governments which are called upon to report upon the level of compliance to the Convention, rather than people with disabilities themselves.

Both Reinders (47) and Nirje (46) have commented upon the limitations inherent in a rights approach. Reinders draws us back to his basic thesis of the importance of caring relationships. He agreed that the rights language has been most effective in opening up "… spaces that remained closed for 'displaced' persons, such as persons with disabilities" (p. 42). However, he has argued that the rights claims are necessary, but not sufficient to counteract exclusion, because they are limited to spaces in the public domain. It is the private sphere where the rights approach has little or no impact. For instance, friendship, the development of relationships, and sharing one's lives are possibly the most fundamental issues, not only for people with disabilities, but for all people. None of these issues can be directly influenced by injunctions from the public domain. Earlier, Reinders (49) commented that, "People can be forced to comply, but they cannot be forced to care" (p. 23).

Nirje (48), often referred to as the "father of the normalization principle", pointed out that,

> "Laws and legislative work cannot provide total answers to problem solving and proper actions with regards to realization of human rights. These can only come into existence in the full cultural and human context. Such problems are not only practical, but also ethical". (p. 65)

One of the problems faced when approaching the international arena of human rights is the differences in cultural heritages among countries of the world. In western cultures, individualism is a predominant force, sometimes for good or bad, whereas many non-western nations emphasize the notion of a person's obligations to the community or tribe more strongly than the individual's rights.

Clapton (50) suggested that the disability rights movement has shifted the socio-political identities of people with disabilities from being seen as "… *objects* of the medical discourse, to *subjects* of the political discourse. … Within the liberal state, there is movement of liberation from welfare recipients to a citizen; and hence is also indicative of the shift from exclusion to belonging". (p.76). In this context, Clapton (25) indicated that inclusion, as a condition for citizenship in a society, is a moral imperative of the disability rights movement.

But Cumella (51) has noted that the concept of citizenship is fraught with difficulties for people with intellectual disability, particularly the question of whether those deemed to have impaired rationality can be considered citizens. He suggested that there was a wide belief in the community that such a stigmatized group was not worthy of determining their own way of life. As a result public policies for this population "… have been shaped by the dominant political ideologies of the day". (p 178)

The Rights discourse has been to a large extent dominated by the voices of people with a physical or sensory disability and it is a moot point whether this approach has contributed significantly to the emancipation of people with intellectual disabilities. Their voices have certainly been muted, although Self Advocacy groups have had some impact and the movement towards inclusive research is gaining strength (52).

Ethical inclusion

The discussion above concerning the moral status of a person with an intellectual disability provides a context for Clapton's concept of ethical inclusion. The acceptance of their personhood is surely a criterion for accepting them into our lives. Reinders (53) noted that the real challenge people with intellectual disabilities pose for us is: "… not so much about what we can do for them, but whether or not we want to be with them…it is not citizenship, but friendship that matters" (p. 5). Nirje (48) possibly encapsulated the essential meaning of ethical inclusion and the genuine acceptance of people with intellectual disabilities in his profound definition of integration (inclusion) as being based on the recognition of a person's integrity, meaning "to be yourself among others -- to be allowed to be yourself among others" (p. 67). The essential message here is acceptance of diversity in the human condition.

Clapton (50) contended that it is not the notion of impaired bodies that presents barriers to ethical inclusion, but it is impaired ethical theorizing, exemplified in the traditional approaches to applied ethics which have implicitly excluded people with intellectual disabilities. This argument resonates with that of Carlson (30) who has indicted philosophers for their lack of interest in the specific nature of a person with intellectual disabilities and ignorance of their lived realities. In fact, she pointed out philosophical discourses have perpetuated certain forms of oppression.

Whilst ethical and philosophical discourses concerning the issue of inclusion are important for this discussion, the quality of the lives of people with intellectual disabilities is also impacted upon by broader economic and political forces, which are seldom commented upon in the disability literature. In studying the processes and outcomes of community inclusion, we have not addressed the situation of people with intellectual disabilities in relation to the wider society in which they live. For instance, many of the issues addressed that relate to prejudice, discrimination and the commodification(i.e., treating people as a commodity) are a part of ordinary psychosocial reality and of everyday life of all people.

Economic and political barriers to inclusion and quality of life

The dominance of market ideology

Neoliberal economic policies of the major industrialized nations (e.g. the G 20), accelerating during the Regan and Thatcher years, have had an impact upon the provision of services for disadvantaged groups. A classic demonstration in the Australian context is the publication of two recent reports by the National Productivity Commission on Ageing and Carers (54) (*Caring for older Australians*) and Disability (55) (*Disability care and support*). The Commission is the Australian Government's independent research and advisory body on a range of economic, social and environmental issues, but with a heavy emphasis upon economic factors. It appears that all social initiatives must be judged primarily upon their economic impact.

Economic rationalist policies are predicated on the principle of "utility maximization", with individuals using their resources to achieve the highest level of satisfaction possible. The essential element is that people must be free to choose how they use their resources - in essence economic reform means reducing interference by governments (e.g. The US Tea Party phenomenon). In this process, strong countries can exploit the weak, while wealthy companies increase their wealth by shopping around the world for the cheapest labor.

One can sympathize with people in developing world countries who are feeling the effects of globalization. McKibben (56) related the case of farmers in Mexico, who were unable, because of so called primitive farming practices, to produce perfectly rounded tomatoes that the newly arrived international shopping chains demanded. They were eventually forced out of farming to join the ranks of the unemployed and the result was the killing of a local industry. The materialization mantra is sapping the lifeblood of those elements which build social cohesion and a sense of mutual obligation towards one's fellow citizens, especially those who are marginalized and relatively powerless. Amartya Sen (13) suggested that the powers of the market economy need to be augmented by the provision of basic social opportunities in a context of social equity and justice.

Brendan Gleeson, director of an urban research program (57), observed that while care goes to the heart of the human experience,

> "The act of care is now an exchange framed around individual consumption power, not social obligation. The power and the autonomy of the cared-for consumer are thus strictly circumscribed by imperatives of exchange: money and realization of profit. In short, deinstitutionalization rendered the socially dependent subjects without agency. This may be emblematic of the wider resubjectification of citizens as consumers under neoliberalism". (p 14)

In countries where neo-liberal policies are struggling under the pressure of reduced welfare budgets, resulting in fewer and less experienced support staff to service a growing number of people in need, there will be an urgent need to consider a re-conceptualization of what care means. The picture is no less bleak in developing countries which are generally copying the failures of the western economic system.

Emphasis upon individualism

The emphasis upon individualism and the associated economic environment have led to society judging the worth of an individual according to the amount one contributes to the economy. It has led to a commoditization of the human condition and is one of the most serious challenges fading those of us who work with people at the margins of society. One might ask whether the tremendous growth in western economies has liberated its citizens?

The rhetorical forces driving the free-market economy present a tantalizingly seductive similarity in their goals and processes to many of the contemporary goals for people with a disability, their caregivers and families. The concepts of freedom of choice, more control over one's life, release from government regulation, self-determination, and empowerment all appear to sit comfortably in both areas. The emphasis upon individualism, however, presents quite a threat to a vulnerable population, such as those with intellectual disability. In our goal to encourage their independence, we have overlooked the essential fact that the vast majority of this population will, in many aspects of their daily lives, remain dependent on supports. Edwards (58) argued that the normative component of individualism compromises the integrity of intellectually disabled individuals and contributes further to their being ascribed a lower moral status than other humans. The individualistic view of the self,militates against people with disabilities as dependence is viewed negatively. However, Reinders (47) pointed out that dependency for people with intellectual disabilities is the *conditio sine quo non* for their physical, mental and spiritual well-being.

The challenge, then, is how do we create environments where the interdependence of individuals is a central feature and where individuals perceive their identity and conceptualization of self in the context of a mutually dependent society?

Quality outcomes

Schalock (59) argued that human services organizations are being increasingly challenged to provide quality services within the context of two powerful, potentially conflicting forces; person-centred values and economic re-structured services. To justify expenditures that are measured objectively, one must demonstrate consumer outcomes. Rather than being collaboratively developed, value systems are imposed by authoritarian administrations.

In much of the administratively dominated delivery systems, we are still witnessing what Burton Blatt (60) so eloquently exposed in his essay on the "bureaucratization of values" in which terms become "mere shibboleths, devoid of their original meanings." (p. 330) Human services are now operated as businesses, replete with a panoply of "business speak" managerialistic jargon that tends to create a veneer of efficiency, but is devoid of the warmth of sound human relationships.

This is not to deny that scarce resources must be applied efficiently to achieve quality outcomes for the people in need. However, who is to determine the nature of the appropriate outcomes and the method of measurement? Have we reached the "tyranny of quality" predicted in 1991 by David Goode (61)?

Despite policy statements concerning quality of life outcomes for people with disabilities, I remain of the opinion that governments continue to apply traditional Quality Assurance models when measuring the standard of service delivery. For instance, in Australia the Commonwealth and several State and Territory governments continue to audit disability services against a set of service standards promulgated to accompany the Commonwealth *Disability Services Act* of 1986 (62). None of these standards addresses quality of life issues. Rather, they are essentially process issues that may be necessary, but not sufficient to ensure quality of life outcomes. Interestingly, the same Act aimed to "enhance the quality of life experienced by people with a disability by assisting them to live as valued and participating members of the community". Government audits do not appear to address either quality of life or the level of meaningful inclusion.

As Guus van Beek (63) from the European Quality in Social Services, has pointed out, there are essential differences between products and services. He suggested that we have adopted a universal paradigm of quality management approaches to social services which are applied in a production and manufacturing environment where there is a tangible product. Here the emphasis is upon clarity in role and responsibilities, process control, efficient use of resources and meeting fixed measurable standardized outcomes based on the demands of the customer. The European Commission defines social services as "essential services directly delivered to a person". Van Beek argued that, unlike a product, a service is intangible. Products are also more likely to be standardized whereas services are tailor-made to individual needs and choices. But as the welfare reform analyst, Jo Anne Schneider (64), commented "…people are not widgets" (p.2).

Jon Pierre and Bo Rothstein (65) of the Quality of Government Institute at the University of Gothenburg concur, arguing that the New Public Management (NPM) is now the preferred model of public administration in most western industrialized countries. They suggested that the basic tenets of NPM, which are directly derived from neo-classical economic theory, encourage not-for-profit social services to emulate the modus operandi of the for-profit sector.

Here citizens become "customers", who if dissatisfied with a service, can vote with their feet and turn to another service provider. This has an interesting parallel with a shift by governments in the UK, Canada and Australia to a system of individualized financial packages directly to a person with a disability, rather than to a service agency. It is argued that competition will encourage a stronger support services system and lead to better outcomes for the person. Again, we see the emphasis upon the individual, rather than to a broader conceptualization of a better society.

The way forward

Conceptualizing social inclusion

Whilst there have been a plethora of attempts to define just what is meant by community, we do not seem to have progressed the analysis in the context of social inclusion. In its early formulation in the generic literature, the concept has been discussed in relation to its opposite – social exclusion. But is this not the very issue Article 19 of the 2006 UN *Convention on the Rights of Persons with Disabilities* (46) addresses? Clause (b) of Article 19 states:

> "Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;"

Whilst this is a clear statement that segregation is not an option, its import does not go beyond the concept of *technical inclusion* alluded to above.

In the eyes of many, including disability support workers, community presence is seen as a physical entity. This has led to quality assurance approaches which measure the notion of inclusion in terms of the number of times a person has actively participated in a community outing. Little regard is given to the subjective elements which may be involved. We have also retained the notion that communities have historically been defined geographically. Modern urban communities reflect a far different scenario, wherein relationships play a more integral role in defining one's community.

In order to progress our thinking and to counter what is perceived as a diminished emphasis upon social inclusion as an outcome, we need to address theoretical and conceptual frameworks which will advance our thinking. For example, the social commentator and member of the Australian Social Inclusion Board, Tony Vinson (66) suggested that the power of social inclusion has stemmed from its flexible interpretation rather than its "analytical clarity". Bigby and Wiesel (67) proposed that we should look to concepts developed by urban researchers to assist the understanding of relationships between place and social interaction in modern cities.

Measurement of well-being

Historically countries have measured the state of their economies by reference to indices such as Gross National Product (GNP) or Gross Domestic Product (GDP), but this does not indicate a population's well-being or happiness, which logically should be the result of economic policy. As early as 1972 the small Himalayan Buddhist Kingdom of Bhutan established a Gross National Happiness Commission to monitor changes in the nation's happiness (68). More recently, Amartya Sen's (13) work on capabilities influenced the development of the Human Development Index by the United Nations. This Index captures capabilities in health, education and income. The combination of economic indicators with social indicators gives a more rounded picture of well-being.

Increasingly, international economic commentators are recognizing the need to focus on a new direction. For example, *Relationships Global,* founded by Michael Schluter (69), is a network of people and organizations which recognize the importance of relationships to human wellbeing, and which seek to combat the causes of relational poverty and build a better world. Relationships Global cited Lindsay Tanner (70), former Australian Government Minister of Finance, who commented that relationships are the missing piece of the political puzzle as we try to adapt to the domination of the bottom line and to the constant economic, social and technological changes. In a similar vein, the commentary of Charles Leadbeater, author and Associate of Demos, Britain's leading cross-party think-tank, was also referenced. Leadbeater highlighted the importance of a sense of identity which depends very much upon relationships, a position I noted earlier in this chapter. He suggested that, "Our sense of identity does not simply come from within – what we want to be – but from our interconnectedness and interdependence" (http://www.relationshipsglobal.net/Web/).

Another indication that there is an expanding world-wide movement to measure happiness and quality of life is the launch by the OECD in 2004 of a Global Project on Measuring the Progress of Societies and its recent launch of Better Life Initiatives in 2011 (71).

The European Union is also establishing its own set of indicators. The French Government recently convened a commission headed by Joseph Stiglitz and Amartya Sen to propose a new set of indicators. In 2010, the UK Government announced it would monitor subjective well-being in annual surveys. In 2001, Robert Cummins (72) developed the Australian Unity Wellbeing as a barometer of Australians' satisfaction with their lives and life.

Regular surveys are made and results published. Even newspapers have seen the usefulness of these types of data, evidenced by the Australian-based *Herald/Age* -Lateral Economics Well-being Index (73) which aggregates individual economic circumstances and happiness into a measure of national social progress.

Building an ethical community

In 1992 John Ralston Saul (74), in his book *Voltaire's Bastards*, argued that Western civilization is without belief for the first time since the decline of the Roman Empire. More recently, Jeffrey Sachs (68) in *The price of civilization, economics and ethics after the* *fall*, echoed the same sentiment. He suggested that there is a moral crisis, a loss of the ethos of social responsibility, and a decline in civic virtue; exemplified by America's hyper-commercialization which is also penetrating other societies, especially the emerging economies. Sachs argued that we need to reclaim our mental balance, because:

> "The logic of profit maximization, combined with unprecedented breakthroughs in information and communication technology, has led to an economy of distraction … the end result is a society of consumer addictions, personal anxieties, growing loneliness in the midst of social networks, and financial distress". (pp. 158-58)

Sachs' antidote is that we need to create "a mindful society" and re-conceive the idea of a good society through multiple acts of good citizenship, "… remembering that compassion is the glue that holds society together" (p. 5). The moral standing of people with intellectual disabilities, however, remains a challenge in a society which strives for perfectionism in body and mind.

Also writing in 1992, Paul Dokecki (75) was sanguine that by the year 2000 we would see the development of an ethical community that would be a counter to what Bellah et al (76) called "ontological individualism". Dokecki argued that "… we should work toward an ethical conception of community, which establishes that all persons are fundamentally equal as human beings" (p. 40). How then might we recapture Dokecki's enthusiasm; despite the continuing materialism, hedonism, privatization, and individualism which is still clearly apparent in our society in the second decade of the millennium?

H Rutherford Turnbull (77) in his keynote address to the annual meeting of the American Association on Mental Retardation in 1998 asserted that each member of a community must recognize that all are vulnerable in some aspects of their lives. As a first step, therefore, the ethical community must recognize what Turnbull eloquently suggested: "a mutuality of need and reciprocity of vulnerability". The increasing emphasis on supporting families and focusing policy research on the family's role in supporting their family member with an intellectual disability is a promising sign that the development of the conception of an ethical community is not a pipe dream never to be achievable.

One critical way in which resources must be directed is towards building community capacity and the development of social capital. Whilst disability policies in the western world are moving strongly toward supporting person-centred planning, individual choice and the allocation of support resources to individuals, rather than to service organizations; there is a danger that generic community resources and natural supports will not be sufficient for personal plans to be realized.

Despite the rhetoric, I sadly believe most current western, and to some extent, developing country government policies remain captured in the belief that market forces result in a more equitable society. As indicated, this is a contestable position and leaves the most vulnerable, including those with intellectual disabilities, dangerously exposed. Hopefully, we shall see a return to a position where governments provide much needed leadership to inspire their communities to a higher plane than self-indulgent materialism.

The quality of life and social inclusion of people with intellectual disabilities will, to a large measure, depend upon external socio-political-economic forces. Their level of acceptance as fellow human beings and citizens will also be influenced by the humanity and compassion of the general community. Those advocating for this population need to engage with the wider community in its journey to quality of life and happiness. Thus far, we have been too focused on the needs of people with intellectual disabilities in isolation from those of the wider community. In other words, we have not been sufficiently strategic in our thinking, our policies or our actions.

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